DOCUMENT RESUME

ED 390 201 EC 304 466

TITLE	The Texas Education Agency Services to Children with Deaf-Blindness: The Texas Project. Final Report.
INSTITUTION	Texas Education Agency, Austin.
SPONS AGENCY	Special Education Programs (ED/OSERS), Washington, DC.
PUB DATE	[95]
NOTE	138p.; For analytics of appendixes, see EC 304 467 and 468.
PUB TYPE	Reports - Descriptive (141)
EDRS PRICE	MF01/PC06 Plus Postage.
DESCRIPTORS	*Deaf Blind; Delivery Systems; Demography; Disability Identification; Elementary Secondary Education; *Family Programs; Incidence; Material Development; *Outreach Programs; Paraprofessional School Personnel; Participant Satisfaction; Postsecondary Education; Program Evaluation; *State Programs; *Teacher Education; *Technical Assistance; Workshops
IDENTIFIERS	*Texas

ABSTRACT

This packet presents the final report and related supporting material of the federally supported Texas Deaf-Blind Project, which provided technical assistance to families of children with deaf-blindness, as well as public and private agencies, institutions, and organizations providing services to this population throughout Texas. During the grant period, the census total of such children increased from 235 to 594. The Deaf-Blind Outreach Team provided on-site consultation to 2,009 professionals and paraprofessionals and 451 family members. Training workshops on local, regional, and statewide levels were attended by 8,554 professionals and 1,384 family members. Preservice training was given to 18 university or alternative teacher certification classes. A lending library circulated 262 items. Quarterly newsletters in either English or Spanish were mailed to 4,288 individuals, including: 683 families. An attached evaluation report concludes that the project is strong and effective with an excellent staff. The evaluation report notes the emergence of two primary issues--the state-wide problem in teacher training in the area of severe disabilities and the complex impact of dual sensory impairment on student learning. Other material includes sample consumer satisfaction surveys, a description and text of a project-developed videotape, samples of six project-developed information pages, "A Brief Guide to Personal Futures Planning" by Kate Moss and David Wiley, census data by region, and sample copies of the newsletter, "P.S. News!!!" in both English and Spanish.
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ED 390 201

The Texas Education Agency

Services to Children with Deaf-Blindness

THE TEXAS PROJECT

FINAL REPORT

CDFA 84.025
State and Multi-State Projects for
Children with Deaf-Blindness

EC304466

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II. Abstract

Through this grant the state of Texas provided technical assistance to families of children with deaf-blindness, as well as public and private agencies, institutions, and organizations providing services to children with deaf-blindness, as described in 34 CFR 307.11. The Texas Deaf-Blind Project provided technical assistance to families and professionals in communities throughout Texas. The Project was designed with objectives and associated activities to meet federal priorities for this project.

The Texas Project consisted of both grant funded and in-kind personnel. The project director is based at the Texas Education Agency in Austin, with staff at Texas Tech University in Lubbock and at the Texas School for the Blind and Visually Impaired (TSBVI) in Austin. The Project coordinated extensively with related agencies and programs throughout the state. Project staff worked in conjunction with 1100 local education agencies, twenty regional Education Service Centers, the Texas Commission for the Blind, Regional Day School Programs for the Deaf, the Helen Keller National Center, the Inter-Agency Task Force for Future Services to Deaf-Blind, and other related organizations.

Project Access, based at Texas Tech University, was designed to increase the number of children identified as meeting the federal definition of deaf-blindness. During the grant period a new process for collecting census data was instituted and the census total increased from 235 to 594. Parents and local programs serving the children identified in the census became eligible to receive technical assistance from the Deaf-Blind Outreach Team, based at TSBVI, to create appropriate support and programming in home, school, and community environments.

The Deaf-Blind Outreach Team provided technical assistance to families and service providers across the state over the past three years in a variety of formats. On-site consultation in schools, homes and community service environments was provided to 2009 professionals and paraprofessionals and 451 family members. 8554 professionals and 1384 family members attended training workshops on local, regional and statewide levels. Training on the pre-service level was given to 18 university or alternative teacher certification classes. 531 individuals received assistance with transportation or child care in order to attend training. Information and referral services by were provided to 4624 persons. This includes dissemination of materials produced by the project, including over 150 copies of videotapes. A lending library circulated 262 items. Quarterly newsletters on topics relating to deaf-blindness were mailed in either English or Spanish to 4288 individuals, including 1683 families.

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IV. Purpose, Goals, and Objectives

The Texas Deaf-Blind Project provided technical assistance to families and service providers statewide in meeting the unique educational needs of children and youth with deaf-blindness. The project focused on technical assistance as state law mandates a free appropriate public education to all deaf-blind students from birth to age 21 (TEC 11.052 and 21.503).

In accordance with the priorities set forth in 34 CFR 307.11 (a)(2) and the *Texas Comprehensive System of Personnel Development Plan*, the purpose of the Texas Deaf-Blind Project was to provide technical assistance in the areas of student identification, preservice, inservice, replication of successful approaches, parental involvement, consultative services, and integration within the context of demonstrated effective practices. The goal of the project was to enhance integrated educational services by supporting and improving local resources, allowing children and youth with deaf-blindness to live, receive an education, work, and fully participate in their communities.

The project had four objectives:

Objective 1) Develop and implement a statewide process for training in the identification and reporting of children with deaf-blindness so that the children and their families will receive appropriate services throughout their lives.
Activity: Implementation of a deaf-blind census process with related training.

Objective 2) Participate, at the request of universities, in preservice training by assisting in the design of course content and presenting on topics that reflect best practices in service delivery to students who are deaf-blind.
Activity: Presentations at personnel preparation programs.

Objective 3) Provide inservice training to educational staff and families which supports functional, age appropriate instruction in integrated environments; train service providers in non-school environments (i.e., community living, employment, daycare and recreational settings); and train staff members at human service and community service agencies so that staff members can provide appropriate supports for children with deaf-blindness while they are school age and as they transition to adult life in the community.
Activities: Training in the INSITE curriculum; on-site consultation; regional and local workshops; an annual statewide conference; lending library; and information and referral services.

Objective 4) Provide training and support for families of children with deaf-blindness to facilitate their involvement in the education and post-school transition of their children.
Activities: Training in Personal Futures Planning, individual family training, a quarterly newsletter, and workshops for families.

Project Access had primary responsibility for the activity designed to meet Objective One, developing and implementing a new census process.

Deaf-Blind Outreach had primary responsibility for Objectives 2-4 and the thirteen associated activities. A transdisciplinary team consisted of a parent training coordinator, transition specialist, INSITE/early childhood specialist, three education specialists, and a clerical support person. This team carried out the activities to support grant objectives in the areas of preservice, inservice, and family services, in order to meet the needs of families and professionals serving Texas children and youth who are deaf-blind. Supervision of the team was provided in-kind.

The Deaf-Blind Outreach Team based in Austin provided technical assistance through site-based intervention, training workshops and conferences on local, regional and statewide levels, pre-service coursework, transition consultations, family training and support, a lending library, dissemination of training materials, and a quarterly newsletter.

V. Conceptual Framework

The grant project was based on the published federal priorities. It was designed based on literature regarding best practices, consultation, and previous experience providing technical assistance to families and service providers of children and youth with deaf-blindness. Grant personnel developed this approach over many years being guided by the principle that technical assistance is most effective when a state has a stable base of expertise about deaf-blindness regularly available to serve as a resource and respond to needs on the local level.

The consultation model used involves a professional in deaf-blindness providing training to a range of people surrounding an individual student, including administrators, teachers, related service providers, and family members. This model creates a trained team at the local level to implement the best practice strategies recommended by the consultant.

The structure of the project and grant activities were developed through needs assessment and evaluation. Consultation provided by national technical assistance organizations such as NECTAS and TRACES (TASH-TA) help focus grant activities. During this grant cycle, an additional outside evaluator, Dr. Kent Logan, was consulted to further improve the design of grant activities. As a result, this 307.11 project resembles the model for state projects described by Michael Collins in *Deaf-Blind Perspectives,* Winter 1994-95.

VI. Accomplishments

The Texas Project was able to enhance integrated educational services by empowering service providers and families on the local level through the completion of the following objectives and activities.

Objective 1: Census
Develop and implement a statewide process for training in the identification and reporting of children with deaf-blindness so that the children and their families will receive appropriate services throughout their lives.

Activity 1: Develop and implement a process for statewide training in the identification of children with deaf-blindness and collect data on those identified children.

Accomplishments: The Census process was implemented in all 20 education regions in the state through presentations in each region, telephone contact and mail. The number of students with deaf-blindness reported increased 160% in the three year project.

Objective 2: Preservice
Participate, at the request of universities, in preservice training by assisting in the design of course content and presenting on topics that reflect best practices in service delivery to students who are deaf-blind.

Activity 2: Participate in preservice course work on deaf-blindness at universities and colleges across the state.

Accomplishments: Deaf-Blind Outreach team members made presentations or consultations to a total of 8661 students and professionals in eighteen classes at universities, colleges, or alternative teacher certification programs. Programs impacted involved students training in the areas of rehabilitation, special education, education for the visually impaired, speech and hearing, and paraprofessional development. Programs were located at Texas Tech University, the University of Texas, Southwestern University, San Antonio Community College, Southwest Collegiate Institute for the Deaf, and alternative programs at several regional Education Service Centers. Additionally, many university faculty and students attended one or more of the workshops, conferences, and symposiums on deaf-blindness sponsored by the Texas Project.

For example, the Transition Specialist conferred on issues related to deaf-blindness with faculty and students at the Southwest Collegiate Institute for the Deaf at Big Spring. This school has programs to certify deaf students for paraprofessional positions in education and human services, as well as to certify sign language interpreters. Assistance was provided to annually bring students and faculty of SWCID to the Conference on Deaf-Blindness and Multiple

Disabilities, the workshop on transition planning, or the Symposium on Deaf-Blindness. The transition specialist organized a tour of three model programs for students to observe paraprofessionals and interpreters working with individuals who are deaf-blind.

In addition to supporting regular Texas preservice programs, four of the Texas Project staff taught a portion of the curriculum for the 1995 South Central Summer Institute on Deaf-Blindness. This graduate level course was sponsored by the Perkins National Training Project and Texas Tech University.

Objective 3: Inservice

Provide inservice training to educational staff and families which supports functional, age appropriate instruction in integrated environments; train service providers in non-school environments (i.e., community living, employment, daycare and recreational settings); and train staff members at human service and community service agencies so that staff members can provide appropriate supports for children with deaf-blindness while they are school age and as they transition to adult life in the community.

Activity 3a: To continue training and follow-up in the INSITE curriculum to local service providers across the state.

Accomplishments: Five or six day trainings in the INSITE curriculum for early childhood were offered at 14 locations throughout the state during the three year grant cycle, with 433 total participants. Abbreviated 1-3 day trainings in INSITE or related early childhood topics were presented at an additional 16 locations, including the annual statewide ECI conference. Early childhood presentations were included at each annual Conference on Deaf-Blindness and Multiple Disabilities to enrich the information available to service providers and families with young children.

By attending one on the INSITE trainings, the Laredo Early Childhood Intervention team learned about Lilli Nielsen's "Little Room." The Laredo team decided that twelve children could benefit from a homemade version of the "Little Room." They raised $1,275.00 from the community to purchase materials to make 12 of the homemade "Little Rooms" to be placed in the childrens' homes and 1 to be placed at their center. A retired principal helped coordinate the construction of the rooms through a high school shop class. When the rooms were constructed, the Laredo Early Childhood Intervention team held an open house to display the rooms and to acknowledge the community effort which made the project possible.

Activity 3b: To continue to provide on-site technical assistance to educational programs serving children with deaf-blindness and their families upon request of local agencies.

Accomplishments:
During the three year grant period, the Education Specialists, INSITE Coordinator, and Transition Specialist provided 344 on-site consultations around the state. During the first grant year 546 individuals in 60 school districts received 125 consultations. 556 professionals and paraprofessionals took part in 104 consultations in 49 districts during year two. An additional 115 consultations provided training to 747 professionals and paraprofessionals during the third year. Some districts took part in training plans through two or three of the grant years.

The Family Training Coordinator often worked together with other team members to provide training to family members during consultations. In all cases, the family was considered an integral part of the consultation. Deaf-Blind Outreach requests that parents be invited to all on-site training opportunities at local schools. There are many examples of positive outcomes from the consultation provided by the Texas Project during the three year grant period. Examples include:

A school district serving a student with deaf blindness joined the family in expressing a strong concern that the student was not receiving appropriate programming. The education specialist designed a training plan for the staff. However, the training needs of the school staff and the logistics involved with the delivery of training were so extensive, that the child was in danger of losing almost a year of programming. Because of this, the Education Specialist recommended that an intervenor be designated to work with the student and be the recipient of a concentrated technical assistance effort. The district agreed and as a result the student made dramatic progress in one semester. The intervenor has also served as an effective support on the local level to all staff associated with the child.

Another training plan improved educational services for 15 year old student with deaf-blindness in a West Texas city of approximately 20,000 people. Before the family received training from the Deaf-Blind Outreach Team, the student had been with the same teacher for 5 years, in a self-contained elementary school classroom. His educational day consisted primarily of practicing isolated skills such as supervised gross motor exercises (i.e. stand up, sit down, stand up), walking the hallways without a destination to practice using a pre-cane device, and fine motor object manipulation (e.g. placing blocks in a bucket).

Due in part to technical assistance provided by Deaf-Blind Outreach, this student's educational placement changed to the high school, where he received individual support by an aide for 70% of his day. He began using an object calendar to anticipate scheduled events and actively participates in functional activity routines, around and with both disabled and non disabled peers. His aide supported him in several school environments, including regular education classes. This student's parents have become better able to knowledgeably advocate on their son's behalf, in his school and community.

In another case, through consultation with Deaf-Blind Outreach the Texas School for the Deaf developed a vision committee to develop a process for appropriately addressing the needs of the students with deaf-blindness on campus at the time, as well as the students around the state referred to that agency for assessment. As a result, a vision teacher was hired to identify, assess, and support fourteen students with deaf-blindness. Training plans were developed to enable the students to effectively participate in ophthalmological and clinical low vision assessments. A proposal to conduct a school-wide screening for Usher Syndrome was accepted and will be implemented in 1996.

Activity 3c: To provide presentations in content areas based on demonstrated need and indicators of best practice.

Accomplishments:
During this three year grant period, the Deaf-Blind Outreach Team members made a total of 171 workshop or conference presentations to 9,938 participants (1,384 family members and 8,554 professionals and paraprofessionals) across the state. Topics focused on issues related to deaf-blindness including: positive behavior supports, van Dijk methodology, inclusion, tactile symbols, communication, audiology, sexuality, adaptive technology, transition, the use of intervenors, active learning, adapting materials and curriculum, training for paraprofessionals, developing videotape profiles, biobehavioral states, advocacy for families, auditory skill development, assessment issues for students with deaf-blindness, and the visual considerations in using sign language, among others. These presentations took place at events throughout all twenty of the Education Service Center regions.

In addition to the numerous workshops for local and regional audiences, the Texas Project sponsored statewide workshops such as an annual weekend training on transition planning for students with deaf-blindness. The project co-sponsored statewide workshops featuring Dr. Jan van Dijk of the Netherlands and Dr. Lilli Nielsen of Denmark. Additional statewide workshops sponsored by the Texas Project focused on the topics of transdisciplinary teaming and sleep disorders. Two statewide learning and planning meetings on the intervenor model were held. Deaf-Blind Outreach annually co-sponsored a two-day conference in Texarkana, "Visions for the Future", which included information for professionals and family members.

Assistance with travel and child care expenses were provided if needed to permit participants to attend. Workshop materials were made available in accessible formats. Interpreters for both sign language and Spanish were available at project sponsored workshops.

Activity 3d: To continue the statewide conference, focusing on state-of-the-art services and other issues related to children and youth with deaf-blindness, for professionals and families.

Accomplishments: Over the three years of the grant period 1603 individuals attended two day training conferences on deaf-blindness held on an annual basis. This number includes 211 family members. The Texas Project provided assistance with travel or child care expenses for a large number of family members who attended. Conference presentations were translated using headsets for Spanish speaking families. These statewide conferences featured leaders in the field from around the country presenting on a variety of topics.

The Eighth Annual Conference on Deaf-Blindness and Multiple Disabilities was sponsored on February 26-27, 1993 at the Doubletree Hotel in Austin. Over 23 sessions were presented to 650 professionals and paraprofessionals and 50 parents. The focus of the conference was effective inclusion. Other topics were included in the agenda. The selection of topics was in response to needs assessments.

The Ninth Annual Conference was sponsored on February 25-26, 1994 at the Hyatt Regency Hotel in Austin. Over 32 sessions were presented to 792 participants (670 professionals and paraprofessionals and 122 parents). The focus of the conference was quality programming and long term services for children and youth with deaf-blindness. The selection of topics were again in response to needs assessments of conference participants.

The 1995 Symposium on Deaf-Blindness was held June 23-24, 1995 at the Howard Johnson Plaza Hotel in Austin. 122 professionals and 39 family members attended the symposium. The agenda focused on case studies of several children and youth with deaf-blindness and the strategies used for quality education and transition experiences. The symposium format was scaled back from previous years in order to focus more specifically on sensory issues and appropriate modifications unique to deaf-blindness.

Activity 3e: To continue to provide training and on-site consultations for community and human service personnel to help them better meet the needs for support of individuals with deaf-blindness who are transitioning into their agencies.

Accomplishments: The Transition Specialist provided training to 76 staff members during 13 on-site visits to 8 community residential or employment programs. Site visits focused on such issues as developing transition plans, person-centered planning, and developing appropriate programming, including residential, vocational, and leisure programming, for individuals with deaf-blindness. The Transition Specialist also worked within the context of interagency groups such as the Texas Transition Task Force, the Interagency Task

Force for Future Service for Deaf-Blind, and Texas Rehabilitation Commission Deaf-Blind Advisory Board to improve systems for helping youth with deafblindness transition effectively from school to adult services.

For example, the Transition Specialist instituted Project Service Link through *P.S. News!!!*, the Deaf-Blind Outreach newsletter, in an effort to identify transition-aged students and families seeking residential and in-home living supports. Deaf-Blind Outreach contacted the Texas Commission for the Blind and the Texas Rehabilitation Commission, and these three organizations formed an interagency working group to help individuals with deaf-blindness find quality residential support. Project Service Link evolved into the official referral list for the newly created Texas Medicaid Waiver for People with Deaf-Blindness and Multiple Disabilities. Some of the young adults with deaf-blindness identified by Deaf-Blind Outreach after the first article in *P.S. News!!!* are currently receiving residential supports through this Medicaid waiver program.

Activity 3f: To expand and maintain the lending library which provides books, videos, and other materials related to children with deaf-blindness and their families.

Accomplishments: The project maintained a library of books and videotapes reflecting best practice and current trends in education and rehabilitation. During the three years of the grant, a total of 262 items were checked out by individuals across the state. Copies of materials developed by grant personnel were distributed free of charge upon request.

Activity 3g: To continue to provide information and referral assistance to families and professionals.

Accomplishments: A total of 4634 individuals contacted the Deaf-Blind Outreach Team for information. Examples of requests include information on specific syndromes, articles on communication, toilet training and behavior. There were also frequent requests for resources on respite and home services. A toll free number is utilized to assist individuals around the state in requesting information. The newsletter also offered resources through articles and the classified section.

Objective 4: Family training and support
Provide training and support for families of children with deaf-blindness to facilitate their involvement in the education and post-school transition of their children.

Activity 4a: The Family Training Coordinator and the Transition Specialist will identify and train a network of individuals around the state who can facilitate Personal Futures Planning for children with deaf-blindness and their families.

Accomplishments: The Transition Specialist and Family Training Coordinator made a total of 17 visits to 11 sites to facilitate Personal Futures Plans for students with deaf-blindness. They also presented information at local, state, and out-of-state workshops, conferences and summer institutes to persons interested in learning more about this process. Although individuals expressed an interest in learning to facilitate these planning meetings, because of the time and level of commitment involved in the process, a network of trained facilitators did not develop. However, the plans that have been facilitated by the Texas Project have produced positive results for individuals with deaf-blindness and their families.

For example, a Personal Futures Plan was facilitated for a teenager with deaf-blindness who is a student in Bryan I.S.D. His family was involved in a long standing conflict with the district over the unique services they wanted for their son because of his dual-sensory impairment. Much of the communication between the parents and the school had been hostile. The Transition Specialist and the Family Training Coordinator facilitated a Personal Futures Plan for this student to provide training in this process to both the district staff and the family. Personal Futures Planning provided an informal yet structured environment for the family and school to plan amicably. Through this process the group was able to help devise plans for the student's vocational training, clarify his educational goals, and encourage opportunities for developing social relationships. The Transition Specialist continued to facilitate planning group meetings for over two years.

Activity 4b: Continue to provide family training in a variety of areas including developing advocacy skills, understanding and accessing service systems, and specific content areas such as communication, feeding, etc.

Accomplishments: The Family Training Coordinator consulted with 107 family members during the three year grant period. She participated in 36 on-site visits across 21 school districts. The Transition Specialist consulted with an additional 44 family members and completed 15 site-visits to meet with families. All Deaf-Blind Outreach Team members regularly involve family members in on-site visits to schools. In all, 451 family members participated in on-site training in their home or in their child's school during the three year grant period.

These consultations helped empower many families. For example, one of the difficulties faced by educational and human service staff, as well as the technical assistance consultants, comes when they work with a family that is non-English speaking. Through the use of grant funds, Texas Deaf-Blind Outreach staff provided a Spanish language interpreter to assist a single mother in participating fully in a planning meeting which involved representatives from the Texas Commission for the Blind, the regional Education Service Center, a Texas Mental Health Mental Retardation Early Childhood Intervention program, and the Texas Deaf-Blind Project. Only a few of the staff involved with this family can speak Spanish. Using these staff members to interpret at previous meetings had proved ineffective because they did not function strictly as an interpreter and were not bound by the code of ethics that prevent certified interpreters from expressing opinions about what is being discussed. Because the professional interpreters were not employees of the agencies or one of her extended family members, the mother felt empowered to ask and respond to questions as the discussion progressed. As a result of having a professional interpreter, both the parent and professionals commented on the new level of understanding they achieved about each other's concerns and desires for the child with deaf-blindness .

Activity 4c: Provide a quarterly newsletter which serves as a link for families, provides information on sibling and extended family issues, allows a forum for families and professionals to express their concerns, and serves as a statewide information resource.

Accomplishments: *P.S. News!!!* is the quarterly newsletter of the Texas Project. It is edited by the Family Training Coordinator with assistance from the clerical support person. The newsletter included articles written by project staff as well as articles by other people involved with deaf-blindness in Texas, including parents. In addition to articles, classified ads inform subscribers about resources and upcoming events, as well allowing parents to network with others in the state. *P.S. News!!!* is available in both English and Spanish, and in a variety of accessible formats.

During the three years of the grant, 38,462 newsletters were mailed to a list that grew to a total of 4,288 individuals, including 1,683 families. Numerous other national, statewide, and local publications requested permission to reprint articles from *P.S. News!!!*. Consumer satisfaction surveys were sent out annually to assure that the newsletter met the needs of consumers in the state. Feedback from readers indicates that the newsletter plays an important role for families.

For example, one parent of a young deaf-blind child wrote with the following feedback. "I don't know how the people at *P.S. News!!!* always know just what to write about, just when I need it! I also get good resources and info from the classified section.... When you have a child who is dual sensory impaired, multihandicapped, you feel very isolated. Even from parents of children with other types of disabilities. *P.S. News!!!* comes...and helps me to know, yes, there is somebody out there who knows what we live. Some months this newsletter is the only time I know somebody is out there!" This same parent has shared her family experiences with others through articles she has written for *P.S. News!!!*.

Activity 4d: To continue to sponsor or co-sponsor workshops for families of children with deaf-blindness based on need.

Accomplishments: The Family Training Coordinator and the Transition Specialist sponsored or co-sponsored 23 workshops targeting families. Families were also welcome to attend all training provided by the team, including the Statewide Conference on Deaf-Blindness and Multiple Disabilities. In all, 1384 family members attended conferences and workshops sponsored or co-sponsored by the Texas Project over the three years of the grant. A number of the families who attended workshops or conferences were Spanish-speaking, and required interpreters that were provided through grant funding. Support in accessing training was also provided to families in the form of assistance with child care and/or travel expenses for 345 family members. The Family Training Coordinator facilitated additional families in obtaining assistance with expenses from other sources.

The following are examples of accomplishments from workshops that were hosted or presented:
- a family formed a successful on-going Personal Futures Planning circle which assisted a student who is deaf-blind to more successfully move from Jr. High to High School in an inclusive setting.
- a parent who had thought she alone was responsible for her son having Usher's Syndrome learned for the first time it was not her fault;
- a foster parent who was not sure if she could keep a child who was deaf-blind received information and an on-site visit which encouraged her to believe she could care for the child. Several months later she came to her first workshop on deaf-blindness and is now advocating her child, who has since adopted, to be educated in an inclusive setting. She would not have been able to attend the conference without assistance with childcare expenses. With the knowledge she gained, she has become a strong advocate for all children with severe disabilities.

VII. Problems and Resolutions

INSITE: INSITE trainings were designed to be presented in three day blocks in successive months for a total of six training days. This time frame presented difficulties for some programs in releasing staff for such extensive staff development time. The INSITE coordinator varied this design to evaluate a 5 day block of training with the auditory and visual impairment section condensed into one day. Additional one, two, or three day trainings were delivered to meet the need of specific areas in the state. This flexibility allowed a greater number of individuals to be trained on early childhood issues.

Conference: Following an independent evaluation of the grant project by Dr. Kent Logan, the decision was made to dramatically change the size and focus of the annual conference. This conference had grown in size every year and become the only statewide conference to focus on individuals with multiple disabilities. However, many of the participants did not work directly with individuals with deaf-blindness or have a family member who was deaf-blind. It was decided that the Deaf-Blind Outreach Team would seek support from the Texas Education Agency, Early Childhood Education, Education Service Centers, and others to hold an annual conference on students with severe and multiple disabilities. The Deaf-Blind Outreach Team contacted these other parties to propose such a conference, and offered to contribute to planning a strand of presentations focusing on issues related to deaf-blindness.

Instead of the larger conference, the project hosted a Symposium on Deaf-Blindness in June of 1995. Only individuals currently serving or planning to serve individuals with deaf-blindness and family members of these individuals were targeted to be participants. Symposium sessions related directly to sensory issues in relation to assessment and educational programming for individuals who are deaf-blind. As a result, the program was much more focused on issues unique to deaf-blindness.

Agencies: Human service agencies and providers were a significant challenge to this technical assistance model. Because adult services are not mandated, many service providers choose not to serve individuals who require additional staff training. Staffing patterns and high staff turnover make training logistically difficult. Consequently, there was not much demand for training among community service providers. The Transition Specialist determined that work within the context of interagency groups to influence the service system was more fruitful than providing in-service training to individual staff.

The Transition Specialist served on the advisory board for a new Medicaid Waiver support program dedicated to adults with deaf-blindness in Texas. Through this board he influenced the regulations and standards written for the new waiver, including the initiation of training on deaf-blindness for service providers that is mandated by the funding source. He helped develop and participated in a train the trainers staff development model for program supervisors of all Deaf-Blind Waiver providers. Through this board, the Transition Specialist has provided training for those individuals who will survey the waiver service providers to determine the quality of services provided to individual who are deaf-blind. This training helped to make this program an excellent service option for students with deaf-blindness as they transition to adult life.

Additionally, the Transition Specialist developed information and training packages on issues related to deaf-blindness for human service providers. Through the cooperation of the statewide deaf-blind task force, these materials have been made available to the central office of the Texas Department of Mental Health and Mental Retardation, as well as all program providers for the Texas Waiver for Deaf-Blindness and Multiple Disabilities..

Lending Library: Many materials from the lending library became lost upon check-out. As prices went up, replacing these items became more difficult. The time and effort involved with tracking down unreturned materials, as well as the general management of the library, seemed to exceed the benefit to consumers. Consequently, as of the third grant year the library was no longer advertised. The materials were lent on a case by case basis to professionals and families with whom the project staff were familiar, in order to support other training objectives.

Personal Futures Planning: Because of the difficulty in finding individuals who were able to serve as local facilitators, the emphasis on training a network of facilitators was reduced. Instead the Transition Specialist and the Family Training Coordinator facilitated plans as needed for individual students in support of family training goals. A model which employs many elements of person-centered planning was developed for sites which were unable to embrace the entire process. Deaf-Blind Outreach staff continued to advocate for agencies, school districts, and other organizations to consider including the responsibility of conducting these plans into an existing job description.

VIII. Evaluation Findings

In completing this three year grant, the Texas Project has arrived at or confirmed a number of conclusions. These conclusions are based on the experience of the grant personnel and evaluation of grant activities. In addition to participant evaluation of individual activities, an outside party evaluated the project in 1994.

The Texas Project has confirmed that there is an on-going need for experienced professionals in the field of deaf-blindness to serve as a resource in the state. Because of issues such as professional isolation and personnel turnover, professionals in the state will continue to need assistance in providing quality services to students with a low incidence disability. This on-going need is found in both rural and urban areas. New families are also continually identified as needing support, information, and training. Efforts to create local teams with expertise in deaf-blindness are helpful, but will not replace the presence of a strong statewide technical assistance project.

The evaluation of project activities confirms that a wide array of technical assistance activities provided in a coordinated fashion is a good model for these services. Student identification, pre-service training, workshops, on-site consultation, information and referral, and product development to support these activities, all inter-relate in meeting a diversity of needs. For example, a teacher attending a conference may request on-site assistance, leading into a request for more information, which results in attending a more in-depth workshop.

Finally, the project showed the importance of involving all interested parties in training activities. Technical assistance was most successful when professionals from a variety of disciplines and agencies as well as the family, all received training surrounding an individual child. As the grant period progressed, project staff placed increasing emphasis on this transdisciplinary teaming.

Dr. Kent Logan's outside evaluation of the Texas Project, covers these and other issues in great detail.

IX. Impact

The Texas Deaf-Blind Project has had a notable and lasting impact on the field of education for children with deaf-blindness and their families in addition to the completion of the technical assistance activities for children in Texas as listed in "Accomplishments" above.

- *Project staff have produced and disseminated a wide variety of training and informational materials.*

Grant personnel disseminated information to a broad audience through the *P.S. News!!!* newsletter. The newsletter includes articles about a wide range of issues related to deaf-blindness written by project staff as well as other professionals and family members from Texas. Among the 4288 subscribers to *P.S. News!!!* were 248 recipients from outside Texas. *P.S. News!!!* was requested and received in 43 states, the District of Columbia, and three foreign countries. All 307.11 Project Directors from the South Central TRACES region, as well as a number of additional states received, and continue to receive, this quarterly. Fifty-five copies of each issue were sent to the Texas State Library to be made available at libraries throughout Texas.

Newsletter articles written for *P. S. News!!!* and other materials written by project staff are highly regarded, and have been reprinted in a number of national publications. For instance, during the grant period, articles have been reprinted in: *Deaf-Blind Perspectives* (Winter '93); *Traces* (Spring '93); NFADB *News from Advocates for Deaf-Blind* (Spring '95, Summer '95); *SKI-HI Institute Newsletter* (January '95); newsletter of the American Association for Home-Based Early Interventionists (Summer '94); and *Keeping in Touch* (Alaska's 307.11 project newsletter, Spring '94)

A collection of approximately twenty articles written by project staff, supplemented by additional pertinent materials on deaf-blindness, were compiled and disseminated as a package entitled *A Collection of Readings on Deaf-Blindness*. One of these packages was made available to every 307.11 program at the Project Director's Meeting, and over 200 were distributed to families and professionals at workshops.

Additionally, grant personnel created a training video, *Ain't Misbehavin'*, which illustrated the link between challenging behavior and communication for students who are deaf-blind. The videotape offers concrete strategies to positively influence behavior through improving communication skills, offering students more influence over daily events, and improving students' quality of life.

Ain't Misbehavin' was copied upon request, free of charge onto blank videotapes supplied by the recipients. A total of 160 copies of *Ain't Misbehavin'* were distributed during the grant period to 37 states and 3 foreign countries. Because recipients are encouraged to freely copy and share the tape, an undetermined number of additional videotapes are being used nationwide. This videotape was suggested as a resource in nationally distributed *Deaf-Blind Perspectives* and the *SKI-HI Institute Newsletter*.

During the 1992-1995 grant cycle, the Deaf-Blind Outreach Team has developed or updated a variety of additional materials for distribution. All materials have been distributed without charge. Sample copies of some materials have been included in the appendix.

- *Project staff have offered presentations at national forums.*

During the three year grant period, Texas Project staff have made presentations at the TRACES regional meeting, The National Deaf-Blind Project Directors' meeting, and the southwest regional AER conference. During the summer of 1995, project personnel submitted papers to an international conference on deaf-blindness to be held in Vancouver in spring, 1996. Six papers submitted by the Texas Project were accepted for presentation at the conference. A seventh presentation was solicited by conference organizers based on literature published in *P.S. News!!!*

The Perkins National Deaf-Blind Training Project hosted the South Central Summer Institute on Deaf-Blindness in collaboration with Texas Tech University in Lubbock. Individuals from a seven state area received graduate credit for attending. Four members of the Texas Project Staff participated in teaching Institute classes during the summer of 1995.

- *Project staff participated in introducing new ideas from around the world to Texas, by inviting distinguished lecturers.*

The Texas Project brought several speakers with fresh ideas from around the country to conferences and workshops each year. Three presentations from this grant period stand out. The project sponsored or co-sponsored statewide workshops featuring Dr. Jan van Dijk of the Netherlands, Dr. Lilli Nielsen of Denmark, and Evelyn Guyer of New York.

Deaf-Blind Outreach and Region 20 Educational Service Center sponsored Dr. van Dijk for two and one half days of lectures in San Antonio, in April, 1994. By sharing his classic theories and new insights about deaf-blindness, Dr. van Dijk re-energized many Texans who have used his methodologies.

In May 1994 Dr. Lilli Nielson came to Dallas for five days of lectures through the sponsorship of Texas Deaf-Blind Outreach and the Blind Children's Fund. Dr. Nielson conducted both introductory and advanced classes on active learning and the use of the "Little Room." 214 professionals and 15 family members attended the introductory session. 87 professionals and 10 family members attended the advanced. Her techniques were new to Texas, but are now being widely and successfully used due to this workshop and extensive follow-up training organized by Deaf-Blind Outreach.

Evelyn Guyer presented two days of training in Austin in March, 1995. She introduced the techniques of BART (bonding and relaxation techniques) to 29 professionals and 4 family members. These techniques of infant massage for children with deaf-blindness were well received, and other organizations have sponsored her return to Texas for several workshops around the state based on the March presentations facilitated by the Texas Project.

X. Further Information

Further information about these issues is available though national clearinghouses such as ERIC and DB-Link.

XI. Assurance Statement

This report has been sent to ERIC.

JUL 07 1994
SPECIAL EDUCATION

FINAL REPORT
TEXAS EDUCATION AGENCY
DEAF-BLIND OUTREACH PROJECT EVALUATION

JULY, 1994

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TEXAS DEAF-BLIND OUTREACH PROJECT EVALUATION
FINAL REPORT

Kent R. Logan, Ph.D.
Evaluator

OUTLINE

I. Purpose
II. Process
III. Results
IV. Recommendations
V. Ideas for Grant Proposal

I. PURPOSE

This evaluation had three major objectives. The first was to evaluate the current types and levels of ongoing technical assistance (TA) provided by the Deaf-Blind Outreach Staff (DBOS). I looked for both strengths and areas for improvement. The second was to review the census procedure and data and assist DBOS in connecting the census to the focus for technical assistance. The third was to provide an avenue for discussing how the DBOS (including KC Dignan at TEA and Roseanna Davidson at Texas Tech) could develop a comprehensive grant proposal for the upcoming deaf-blind projects funded by the Office of Special Education and Rehabilitation.

II. PROCESS FOR THE EVALUATION

In order to accomplish these three objectives I completed the following tasks:

A. Paper work review. I reviewed the current grant proposal and census procedures and data. I studied how current TA was developed and evaluated and examined the state wide pattern of TA. I did not review evaluations from workshop and conference

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presentations, or training activities such as INSITE. I also did not attempt to evaluate impact of DBOS on interagency groups working on behalf of children and youth with deaf-blindness. This review took place between February and May, 1994. It included phone calls to DBOS. I took extensive notes while reviewing all products. Again, I looked for evidence of processes which would ensure that TA was appropriately developed (assessed) and evaluated, and that the census process would accurately reflect the distribution of DB children and youth in the state

B. On-site visits. I visited teachers in Hooks, Atlanta, and Judson Independent School Districts (ISDs). I met with 6 families who had children in the Judson, Hooks, Atlanta, Alief, Liberty-Eylau, and Bloomberg ISDs. I met with administrators from Northeast, Alamo Heights, and San Antonio ISDs. These on-sites were selected based on my travel schedule rather than a random selection. However, these visits included teachers, parents, and administrators who represented all consumer groups except adult service agencies. They represented all socio-economic and ethnic groups served by DBOS. They also sample they types of TA typically provided by TA organizations. These visits were completed the first week of April and the first week of June, 1994. The format for these on-sites was a structured interview with consumers and observation of classrooms when possible. This structured interview followed the same format as the surveys (Appendix A). However, the interview was wide ranging in its' coverage of the questions. I took comprehensive notes during each interview. I reviewed the notes and summarized consistent themes, including strengths and areas for improvement.

C. Surveys. I mailed out 24 surveys to persons in ISDs, ESCs, and adult agencies who had received TA services. These persons were selected randomly from a list provided by DBOS. Persons who received on-site visits were excluded from the list. These 24 persons sampled over half the TA's provided by DBOS. These surveys were completed in May, 1994. Thirteen surveys were returned for a 54% response rate. This rate is typical for survey responses. The surveys were completed anonymously so it is unknown how many surveys from each consumer group (ISD, ESC, agency) were returned. Responses from rating scales and questions which could be "counted" were tallied. Responses from open ended questions were summarized and listed. Raw scores and summaries are contained in Appendix B.

D. Meetings with DBOS: I met with DBOS over a two and a half day period to share results of A - C above and to discuss DBOS structure and the new grant proposal. This meeting took place May 30 - June 2, 1994.

III. RESULTS

A. Paper Work Review. The current grant project is well structured. All consumers have been targeted for potential services. Staff are appropriately assigned to accomplish grant objectives. Budget is very good, with 74% of budget in personnel. Coordination with other projects and agencies is excellent, especially in the area of working with families. Paper work process for TA development and implementation is also very good. DBOS were able to account for their time and effort and document the TA process.

School or classroom based on-site technical assistance (TA) activities appear to have been conducted in 41 different (ISDs) during the 1993-1994 school year. Over 75 students with deaf-blindness were directly served. Many TA's served multiple students, so the actual number of students was not always clear. These activities occurred in 19 of the 20 Educational Service Center (ESC) Regions. Region 7 was not represented. (See Appendix C). This reflects a good distribution of on-site TA projects across the state. It appeared that overt coordination with the ESC occurred with at least eight of these technical assistance projects.

Separate on-site technical assistance activities appear to have been completed with 13 families. These family TA's do not include routine coordination with the family during on-site school TA. Based on survey and interview information, families are routinely included as part of on-site TA. Over 46 additional families received some type of travel, financial, or phone consultations. This represents an outstanding attempt to meet the needs of families.

I counted approximately 39 workshops or conference presentations that were conducted. These presentations occurred in 17 of 20 ESC Regions. Regions 7, 8, and 14 were not represented. Twelve of these presentations appear to have been directly for an ESC, three for agencies, and the remainder for ISDs. Preservice class presentations appear to have been done at three locations. Coordination with two Alternative Certification Programs appears to have occurred. The annual deaf-blind and multi-handicapped conference was a tremendous success. Based on interviews and surveys, this conference is a very very important state wide training event. These workshops also represent an excellent distribution of training events across the state.

Every effort appears to have been made to develop an accurate registry of children and youth with deaf-blindness. The format for developing the census was excellent. As long as these procedures were followed, the results should be accurate. You can never control for the percentage of responses or the accuracy of what you were sent by the ISD.

I think the numbers are very good. It is my opinion that the federal projection of up to two students with deaf-blindness per 1000 students with special needs is too high. I believe that the higher federal projection over represents students with profound, multiple disabilities. I believe the projection of one per thousand is a more accurate projection. Based on this opinion, the deaf-blind census falls within current projections.

As the table in Appendix D illustrates, there remain problems with defining deaf-blindness, reporting accurate numbers across projected age spans, and getting comparable information across ISDs and ESC Regions. The numbers in the table indicate wide variability in terms of numbers and ages of children and youth reported across the various ESC regions. There are also variations in the data depending on what categories are used to count students. For example one chart lists 68 students ages 16-22 but two others list 101 and 108. My guess is this reflects problems with the data management software rather than errors in finding students. This should be corrected.

After being affiliated with deaf-blind projects for ten years, I don't believe we will ever accurately count this population. Survey respondents don't always interpret the information you send them in the same way. Federal and state definitions differ and that also confuses respondents. Students who are "deaf-blind" overlap with too many other reporting categories. In spite of numerous attempts to define deaf-blindness and separate it from other disability categories, total success escapes us. I think it will continue to escape us. I therefore wouldn't spend time or energy trying to make it perfect, because it never will be.

B. On-site Visits. Interviews and observations reflect the following:

1. Quality of on-site TA is outstanding. Consumer satisfaction is very high.

2. Assessments and evaluations are informal and verbal half the time and formal and written the other half. All should be formal and written as this helps focus the TA and place it within the appropriate context.

3. Administrative support was lacking in one-third of the TA's. A more formal needs assessment and evaluation process would help obtain this support or assist DBOS in deciding whether to provide TA to a site where this support is lacking. I don't believe TA should be provided without administrative support. Without support, the TA ultimately fails, even if a short term effect is obtained. There appeared to be good follow through and consistent implementation of TA recommendations over time when administrative support was present. Supportive administrators incorporated TA training and recommendations into ongoing staff development and supervision.

4. There was good coordination with Commission for the Blind (CFTB) and the ESC when it occurred, which was approximately half the time. This coordination should be increased where ever possible.

5. The TA covered multiple topics (communication, activity based instruction, vision and hearing assessment), and was delivered through multiple avenues (on-site, phone, written information, videos, conference attendance). Three of six parents, and all administrators and teachers said that PS News was an essential component of the TA and continued to be a valuable resource. Half of the persons interviewed had all their PS News in a binder or folder for easy access.

6. All consumers consistently reported that the deaf-blind conference was an essential component in the overall TA. When asked for input on what types of TA could be dropped, all

consumers specifically said "please don't drop the conference".

7. Parents were always invited and usually attended TA events at the ISD.

8. All consumers indicated that there was very serious and widespread lack of training in the area of persons with severe/profound disabilities. DBOS were consistently asked to provide basic information about curriculum and instruction for this population (since at least half of children with deaf-blindness function in the severe/profound range).

9. The itinerant vision teachers played a crucial role in implementing the TA recommendations and providing continuity over time in the TA process.

10. Once the initial on-site was accomplished, all consumers indicated that ongoing phone contact, written materials, and the sharing of videos enabled them to implement and modify the TA over time without a continued need for intensive on-site consultations. All consumers complemented DBOS on being available by phone and being conscientious about returning phone calls.

11. Hispanic cultural issues were not being adequately addressed. However, the respondents who mentioned this issue were not themselves clear about what this actually meant.

12. The availability of services to children birth to five was not always clear to parents. Two parents discussed how they really didn't know what was available to them until their children entered school programs at age five. Services to

infants (0 -2) appear quite fragmented. Unless parents connect with CFTB, they remain unclear about what they can receive. School services to children 3 - 5 also appear unclear to parents.

13. ISD administrators and itinerant vision teachers felt comfortable meeting the needs of students with mild vision and hearing losses.

14. The importance of parental involvement was continually discussed. When parents were involved, appropriate services were developed and implemented.

15. DBOS frequently were mentioned as effective "mediators" between the parents and the ISD.

C. Survey Results. Seven administrators, three itinerant vision teachers, one ESC person, one Regional Day School Program for the Deaf person, and one Diagnostician returned surveys. Over 25 deaf-blind children were directly served by these persons. Most of these students were also severe/profoundly handicapped. These persons received multiple types of TA (on-site, phone, videos, materials, conferences and workshop presentations) covering multiple topics (communication, assessment, curriculum and instruction, impact of sensory loss, making adaptations). The TA typically occurred over multiple days during the school year. Overall consumer satisfaction was 4.4 on a five point scale. Written needs assessments were completed on six of 12 the TA's, verbal assessments on six of 12 the TA's. No assessment was completed on one TA. Evaluations were completed on seven of 13 TA's. Three were written and four were verbal. Families were invited to all TA's. They attended on 12 of the 13 TA's. All consumers wanted more of all types of TA.

One problem was expressed by two respondents. The concern was that school administrators felt that DBOS advocated more strongly on behalf of parents than the school system. They suggested that the TA be delivered through the school system rather than through support of parents. Apparently, the parental request conflicted with what the ISD wanted to provide. This conflict is inevitable when TA providers advocate for appropriate services. A more careful needs assessment process could reduce this problem.

D. Meeting With Staff. The following themes emerged in discussion with DBOS.

1. TSBVI staff have trouble valuing types of TA that are not "on-site". This includes materials and product development and management, information and referral, phone consultations, and interagency coordination. TSBVI staff do too much on-site consultation as a result of this attitude. TSBVI staff are not always clear about how to design a range of TA activities to meet the various needs of consumers.

2. TSBVI staff have too strong a "lone ranger" attitude toward TA. They find it easier to "do it themselves" than coordinate with others. They believe they can resolve too many issues for too many people in too many different locations. This is especially true in the area of curriculum and instruction for

children and youth with severe/profound disabilities. TSBVI staff spend too much time building the initial curriculum foundation for specialized input concerning vision and hearing impairment. TSBVI staff can not solve the severe/profound knowledge gaps statewide by themselves and they should quit trying to do so.

3. TSBVI staff don't have a process for deciding which TA requests they can adequately meet. Staff get "bogged down" in TA's where the primary focus is severe/profound and don't have time to adequately deal with the vision and hearing issues. They also work too much with ISDs where there is inadequate administrative support for the success of the TA.

4. Co-ordination with ESC and CFTB districts varies based on personalities and philosophies of persons in each district. Sometimes it is great, and other times it is simply not possible. This is inevitable and will continue to be the case. Inservice money to ESC's is being reduced. This makes coordination around training issues even more difficult.

5. There is a lack of clear communication and accountability among the three offices of the project (TEA, Texas Tech, and TSBVI). There is no clear chain of command. Feedback among the three groups is inadequate. Project management must occur on a regular basis.

Summary: Overall, the current deaf-blind project is excellent. It is accomplishing all stated objectives. The quality of the TA is outstanding.

IV. RECOMMENDATIONS

A. TEA. Issues related to deaf-blindness are embedded in multiple issues and agencies. This inter-relatedness can best be addressed with a more active role for KC Dignan. I would suggest an increase to .20 FTE for her. As indicated above, there is a lack of coordination and communication among the three offices of the DBOS. Ms. Dignan must be more active in coordinating the project and relating it to state wide initiatives. This would include monthly meetings with TSBVI and Texas Tech staff; assisting in funding projects proposed to her by consumers (e.g., inservice courses, model programs); coordinating with ESC and University committees to address the serious lack of trained personnel in the area of severe/profound disabilities (e.g., summer institute classes with universities, inservice training with ESCs.); becoming active on interagency task forces to advocate for the special needs of children and youth with deaf-blindness at the state level.

B. Census. Every attempt appears to have been made to develop an accurate and comprehensive census. The information is not completely accurate, and it never will be. I wouldn't recommend becoming over involved in trying to obtain a perfect count. The census should be used to provide information to TA providers about children and youth with deaf-blindness. This would include identifying the etiologies, ages, locations, and functioning levels of the students. This information should then be used to direct TA efforts. The census is not an end in and of itself, although it can be informative just to play with the data and see what it may tell us.

1. I think infants and children in the 0-5 group are still under counted. I would focus effort on improving reporting with this group. The other groups can be adequately maintained and updated annually with the survey.

2. Data should be analyzed so that accurate reports can be generated concerning location, ages, etiology, and functioning levels of deaf-blind children. It appears that these children are clustered in certain geographical areas of the state. This information should be used to discuss course work and inservice with universities and ESC's in locations where these children are clustered.

3. The balance of TA should reflect the balance of ages of deaf-blind children. For example, if one-quarter are transition age, than approximately one-quarter of staff effort should be devoted to this age.

4. All DBOS should feel free to call Texas Tech and ask for any analysis of the data. The analysis should be run promptly and mailed to the appropriate person. These analyses should then be made available to appropriate organizations who serve children and youth with deaf-blindness and not only kept "in house".

5. The census indicates that approximately 20% of the population experiences only mild vision and/or hearing losses. Reports from ISDs and itinerant vision and hearing staff indicate they are capable of serving these children. DBOS staff should

not spend too much time with these students.

6. The census appears to indicate that over half the deaf-blind children are also severely/profoundly handicapped. This does **not** mean that DBOS are totally responsible for TA about students with severe/profound disabilities. DBOS should restrict their TA to issues related to vision and hearing impairments as they impact assessment, curriculum, and instruction for these students.

7. Roseanna Davidson should meet regularly with other DBOS. This is difficult because all other DBOS staff are in Austin. However, she has an important role to play on the team and should be included in staff meetings.

8. Feedback about the census should be shared with the families of the children identified. It is possible that children were added to the deaf-blind census without parents knowing about it. Families should be notified about the census, their child's identification as "deaf-blind", and services available to them since their child has dual sensory impairments.

C. Interagency Coordination. Issues related to deaf-blindness affect multiple agencies. These include adult service providers (both public and private), the Interagency Coordinating Council, CSPD, and Commission for the Blind (CFTB). All DBOS should be active in this interagency coordination. This is sometimes tedious and not very exciting work. However, this work can have a tremendous impact. For example, group homes must follow certain regulations. If something is not "in the regs" it typically isn't done. Therefore, the regulations should be written so that issues related to deaf-blindness are present from the beginning. Group homes must comply with the regs. If deaf-blind concerns are addressed in the regs, then group homes must comply with issues related to deaf-blindness. This is clearly more effective TA in the long run than training at any particular group home when the implementation of the training is not mandated by regulations. Issues related to personnel preparation in the area of severe/profound disabilities (both inservice and preservice) might also be better addressed at this interagency or state committee level. I believe that coordination with CFTB is critical since vision services are mandated state-wide. This coordination will be especially critical for identifying and meeting the needs of infants and pre-schoolers.

D. Outreach Staff at TSBVI. TA will continue to be primarily provided by this staff.

1. Staff should conduct a more formal needs assessment and evaluation. This will help focus the TA.

2. Staff should develop a format for deciding when it is appropriate to provide TA. This would include administrative support and a focus on sensory impairments. There should be a clear commitment from administrators to implement and maintain changes made as a result of the TA. Staff should not be providing generic TA in the area of severe/profound disabilities.

3. Staff should work cooperatively with other groups (ESCs and Universities) to develop the foundational knowledge in severe

profound disabilities. I was very impressed with the knowledge and expertise of the itinerant VH teachers trained by Texas Tech and University of Texas. This leads me to believe that similar programs could be developed in the area of severe disabilities. In spite of cutbacks in money and staff, the ESCs could play a central role in alternative certification programs, extension programs with universities (like the VH program), and the development of inservice training in the area of severe disabilities. DBOS should focus efforts on this type of coordination rather than believing that they should be providing direct TA in this area.

4. TA takes many forms: individual consultations, information and referral, materials development and management, training, meetings, and project management. I would like to address each of these forms.

a. **Individual consultations** should continue to be a central form of TA. The focus of these individual consultations should be on sensory issues, rather than generic severe disabilities issues. The interaction of dual sensory impairments with a particular student in a particular environment is very complex and highly individualized. Only individualized consultation can adequately meet these complex, individual needs. However, staff should reduce the number and frequency of on-site consultations. I don't think staff should spend more than half their time "on-site". After an initial on-site visit, staff should assess the needs of the consumers and make decisions about the types of TA which can meet those needs. If the basic problem is lack of appropriate foundational work in severe disabilities, a referral should be made. I know that there are not many other people to refer to in this area. However, there are other agencies, like the ESC, which should and could make this a priority. They will only make this a priority if they are asked by their own consumers to do so.

Staff should also explicitly focus on training local, itinerant vision and hearing, or supervisory staff. It is not possible for TSBVI staff to make enough on site visits to insure success of the TA. Some local person must be trained as a trainer of trainer. My evaluation suggests that when these local persons are trained, TA is more effective over time. There is a high turnover among classroom teachers who teach students with deaf-blindness. It is simply not possible for DBOS to continually train this ever changing staff. Itinerant teachers and supervisors have a low turnover rate. As "trainers" themselves, they can continually train these new teachers.

b. **Information and referral** are critical components of TA. Taking referral seriously will assist staff in making contacts with other people and agencies who may be able to help the consumer. Information can be used to supplement the TA and reinforce what was said and done during the on-site visit.

c. **Appropriately developed and managed materials** can also reduce the necessity of making on-site visits. Staff should prioritize making videos and developing slide tape presentations which can give out basic information. This would include information on calendar boxes, activity based curriculum, and basic functional vision and hearing assessment. Staff clearly cannot meet all requests for in person, on-site TA. Alternative products must be developed and managed to meet the needs of consumers. Time should be set aside to develop these materials. I would make this product development a new grant objective.

d. **Training** is an essential component of the TA process. It is also more "generic" in nature than individual consultation. This training component of the TA could address the issue of severe disabilities as one strand. Other strands could include topics such as functional assessment, communication development (including touch, movement and object cues). I would strongly recommend focusing the TA in geographical (ESC or CFTB) areas where the census shows there is a sizable population of deaf-blind children and coordinating efforts with other agencies and organizations in those areas.

At the preservice level I would focus on TA to the vision and hearing programs at universities. I would not try to provide guest lectures as requested at other programs. As I mentioned above, the quality of VH and AH services is very good in Texas and I would capitalize on that strength. I would also try to establish an ongoing relationship with the ESCs who are working on Alternative Certification Programs. These programs are probably very "generic" and are not covering either severe disabilities or sensory impairments very effectively. DBOS could provide a key role in providing this introductory information. They could also refer the ESCs to other experts in the area of severe disabilities who could also provide this information. And finally, I would focus on trying to work with an ESC/University to develop a summer institute type course in the area of severe disabilities. There are many models for this type of program in other states. These summer institutes are a viable way to address low incidence populations.

At the inservice level, I would recommend focusing training through the ESCs. Since training is more generic, all teachers from a geographical area could attend. I realize that dollars are in short supply and the ESC staff are not always interested in low incidence populations. DBOS staff could form alliances with a couple of ESC's which have been receptive in the past and which contain large number of deaf-blind students. This inservice training should target special education administrators and teachers. It is possible that an ESC could put together a proposal for training and approach KC Dignan for funds. I realize that funds are short, but DBOS can not continue to be the sole provider of information on severe disabilities. I have been contacted by four ESC's over the year for training in this area. Therefore I know there is some level of interest at certain ESC's for this type of training. I think you should actively pursue it and try to find TEA support to fund it.

I would recommend a continued focus on INSITE training. I know that it has been difficult to build the model state wide.

This is good training and will have an impact. Interagency coordination might help in this endeavor.

The Deaf-Blind Multi-Handicapped Conference must be discussed separately. This is a very difficult topic. The importance of this conference was **specifically** mentioned by every single consumer and referenced on **every** single survey as a critical component of TA and often the sole source for information. Therefore, this conference **MUST** continue. The question is...**Who Should Sponsor It?** I don't believe that DBOS should continue to single handedly sponsor this conference. The primary issues addressed by this conference are the generic issues of severe disabilities. I have consistently recommended that DBOS reduce its' TA on this issue.

I therefore strongly recommend that TEA sponsor this conference. This conference is the best of its' kind in the country. It has statewide educational impact. I would further recommend that DBOS provide a deaf-blind strand at this conference.

I would also strongly recommend that DBOS pursue concepts in distance learning. This could be pursued through the state department, the university system, or the ESC network. Texas is a big state and the outreach staff are limited. This staff also has excellent expertise to share with others. Distance learning could also be used to help build the foundation in severe disabilities which all consumers have mentioned as a significant problem state wide.

e. **Meetings** are a critical and not always welcome TA activity. I have discussed the importance of some level of interagency coordination above.

f. **Project management** should become a clearer focus of the DBOS. I would recommend monthly, mandatory meetings.

Hispanic issues must be addressed by the staff. My interviews reflected uncertainty as to what this issue is and how it should be addressed. There are clear cultural issues to be addressed about attitudes and expectations about children with disabilities. These will impact requests for TA and acceptance of TA recommendations. There are also many variations on "hispanic culture" among people whom we identify as hispanic. These concerns must discussed. I would recommend that DBOS hire someone to train them about relevant cross cultural concerns. With this consultant, DBOS can pursue how they should address these concerns. I am not familiar enough with these issues to make concrete recommendations myself.

V. NEW GRANT PROPOSAL

The new grant proposal presents an important challenge. The number of deaf-blind children and youth has doubled. The project will clearly not receive double the money to serve these children. The project may receive a bit more than this year, but not much. It must be remembered that on-site TA reached approximately 100 children and youth with deaf-blindness over the past year out of a total of almost 300 on the registry. Logistically, this number won't increase regardless of the total number on the census. The issues are who should receive this critical type of TA and how can other types of TA meet the needs of the rest of the census population. Clearly, information and referral, materials dissemination, meetings, and training will impact an unknown number of children and youth with deaf-blindness. It would probably impact those persons whether they were or weren't on the census. This is not to say the census is unimportant, because it is. It is only to provide perspective on the problem. The critical thought is to remember that individual consultation will never impact all students on the census, so you shouldn't try or get overly concerned about trying to directly meet all the needs of all 500 children and youth on the census.

I would organize the new project around a matrix which reflects the consumers of TA and the types of TA. This matrix (as outlined below) can become the basis for developing grant objectives and the person-loading chart for the proposal.

	Parents	Early Childhood	ISD	ESC	University	Agency	Census
Info & referral							
Materials Dev & Management							
Individual Consult							
Training							
Meetings							
Grant Management							

These two concepts, consumers and types of TA, are important and they can be confusing. TSBVI staff expressed concern about whether they were appropriately structured to meet unfolding project needs. They also expressed concern that they were focusing their TA energies too exclusively on on-site TA. I think the current structure of the project, which is divided up according to consumer groups, is good and meets the needs of consumers. The current distribution of staff does reflects the distribution of deaf-blind children and youth: one-quarter transition (David), 15% (and probably really 25%) early childhood (Gigi) and one half school age (Jim, Robbie, and Craig) 10% or so Census (Texas Tech) and project management of 50% for Cyral and 10% for KC. As I mentioned above I would move KC up to 20%. Family concerns cut across all the above areas and Kate is full time. It would be appropriate for the new grant proposal to continue to reflect this current staff distribution.

I think the problem is how staff currently divide their time across the types of TA they provide to meet the needs of each consumer group. The focus on the types of TA is out of balance. TSBVI staff spend too much time on on-site TA. In addition, they have focused too much on remediating the state's deficit in severe disabilities. If you keep the current staff distribution, I would recommend the following percentages for types of TA: for school aged personnel, I'd suggest about 40 - 50% individual consultation, 10 - 20% management and meetings, 10 - 20% materials development and management, 20% training and coordination with others for training; for the transition person I would increase the management and meetings since interagency regulations are such a critical part of adult services; for the early childhood person I would increase training due to INSITE and meetings due to the overly complex way these services are delivered across the state, and decrease individual consultation; for the family person I would decrease meetings and increase materials development and management, and continue a high focus on PS NEWS given the positive feedback I received about it. Cyral would obviously have higher percentages in meetings and management and perhaps materials management. Secretarial help would increase in the areas of information and referral and materials management. This should be possible since this position won't be spending as much time on deaf-blind multi-handicapped conference activities.

The new RFP will probably want you to address all the consumers targeted across the top of the matrix. Use your census data to document the distribution of children with deaf-blindness across those consumer groups (number of 0-5, number of school age, number of transition age, number and composition of families, number impacted by various agencies). This will set up your "person-loading" chart to accurately reflect staff effort directed toward meeting the needs different consumer groups.

Analyze the census so you know how many children have mild losses, how many function at what level of cognitive impairment, where these students live, and how many have other multiple physical and health impairments. Use this information to document training and "triage" issues. For example: you don't need to focus on mild losses because local personnel can do it;

you do need to address the severe/profound issue through collaboration with universities and ESC's because it is so broad and is the foundation for sensory adaptations; you can develop training in different geographical areas and with certain universities and ESCs based on the number of children in those areas; you should focus individual consultation on the sensory needs specific children have which can't be met through other types of TA. Use the census data to build a strong case for coordination with the CSPD.

I think it would be important to note that 0 - 5 population is still probably under counted. Obtaining a better count would then become a focus for census activity. Other census activities would be routine maintenance of the census, and providing "data slices" to other staff to clarify the focus for TA and to other agencies to impact their planning.

The last activity I did with DBOS staff was to look at the matrix and brain storm basic grant objectives for each consumer group and relate them to types of TA. I did not bring a copy home with me so I can't summarize it. I trust Cyral and staff have copies. I would like to highlight areas under each consumer group.

Families should be directly addressed. I would focus on empowerment type concerns. Parents make the difference. This was clearly reflected in all my on-site visits. Parents should be taught what they are entitled to and how their child's sensory impairment impacts what they should be receiving. I would stay away from case management activities. You have too many parents to take on that role.

Early childhood is a difficult group to address since so many agencies and organizations deal with this group. I would focus on INSITE training and developing a state wide trainer of trainer network. I would increase participation on the ICC and similar groups. I would coordinate closely with CFTB since they are mandated to serve this population.

The needs of **ISDs** are immense. I would focus individual consultation on the sensory needs of these children within the context of appropriate curriculum. If appropriate curriculum is not in place, I would refer. I would develop a protocol insuring administrative support before providing consultation beyond the first visit. Don't be afraid to say "NO" to systems where there is no commitment. It is not worth the effort without this commitment. After the initial visit and training, rely on phone consultation and the exchange of video tapes for on going TA. Make sure you allocate time to adequately train local itinerant and/or supervisory staff.

I believe there is potential in working with receptive **ESCs**. You can't work with all of them, so select ones who are willing to work with you rather than rely on you. I would develop a protocol for seeking commitment from the ESC just like I would for the ISD. I would focus my inservice training through selected ESCs. I would also focus my preservice coordination with ACP programs through the ESC. Administrative "cultivation" with some ESCs could bring about a good harvest of coordinated training in the area of severe disabilities. These ESCs often have a VH person on staff. Make sure this person is part of all meetings and that he/she is trained as a trainer of trainers.

We discussed the issue of developing regional expertise in the field of deaf-blind. I don't think it is completely realistic to train that many people in such a low incidence population. But, I do think more regional expertise in the area of severe disabilities could be developed. This would be the essential foundation for dual sensory issues for deaf-blind children. I would explore distance learning through the ESC network to provide this type of training.

Universities in other states have taken on leadership roles in training for low incidence populations. I think somewhere in Texas there must be some faculty member in some department at some university who would like to do something in the area of severe disabilities. I think you should really try to find that person. Roseanna can be a resource for this work. A university can do so much in the area of ACP and summer institutes. They could build a basic course in severe disabilities and have DBOS at the end of the course to add the sensory piece on top of the curriculum and instruction base they have built. I would really work with the Texas Tech and UT vision programs. They are turning out some great teachers, and with a little from DBOS during their course work, they could be even greater. The vision network in Texas is strong and good, so build on it for deaf-blind and severe disabilities. I would also explore distance learning through universities to try to meet some training needs of consumers around the state.

Interagency work is critical for systems change. TEA should take the lead in this, but other DBOS should be there as needed.

Project management must also be addressed. I have mentioned above that I think this area has been neglected. Staff should meet regularly to discuss what they are doing and how they can best work together. These times together could also be an opportunity to increase your own expertise. Bring in outside experts to update you on new information. Schedule time for each of you to update your colleagues on issues that you have learned. The bottom line is that you are the experts in dual sensory impairment. Keep up with your field. Consumers will be relying on you for a particular kind of expertise that they simply can't get anywhere else.

CONCLUSION

The Texas deaf-blind project is a strong project with excellent staff. The current project is going very well. The next project will be even more effective. Given the expanded numbers of children and youth with deaf-blindness, project staff will have to focus the TA and value all types of TA to meet the needs of consumers.

The census component can serve to highlight areas for TA and to provide critical information to universities, ESCs, CFTB, adult service providers, and early childhood providers. This can only be done if the information is appropriately analyzed and disseminated. This use and dissemination of the data should be a critical component of the new project.

Throughout all phases of the evaluation, two primary issues emerged. The first was that there is a state wide problem in teacher training in the area of severe disabilities. The second was that dual sensory impairment has a very complex impact on student learning. This impact is highly individualized to particular children in particular environments. It takes highly specialized training to "unpack" this complex interaction and create effective learning environments. The issue of severe disabilities interacts with the deaf-blind issue at many levels. DBOS will have to coordinate more effectively with other organizations to address the needs of consumers in the area of severe disabilities. This coordination will free up staff to conduct the highly complex TA which will meet the needs of children and youth with deaf-blindness.

P.S. NEWS !!!
CONSUMER SATISFACTION SURVEY

We want this newsletter to meet your needs, so we would greatly appreciate hearing from you about P. S. NEWS !!! Please take a moment to complete this survey and return it to us. Thank you for your help.

Are you a parent of a child with special needs? yes
Name (OPTIONAL) Leslie Foster
[redacted]
om's version - a kid with a se[redacted] sensory defecit and a major communication processing problem!

Are you a professional working with special needs populations? not yet
Please describe your role and list the agency or organization for which you work.

Please circle the number below each question that best describes your feelings about the newsletter.

1. During the past year were the newsletters informative?

[✓ 1 Very Informative] 2 Basically Informative 3 Not too Informative 4 Not at all Informative

2. During the past year were the newsletters relevant to you?

[redacted]
[✓ 1 Very Relevant] 2 Basically Relevant 3 Not too Relevant 4 Not at all Relevant

[redacted] ally been clear and understandable?

[✓ 1 Very Clear] 2 Clear 3 4

4. In the future, I would like to see articles concerning:

Eating - help, what adisaster! I'm talking about basic eating habits, eating with fingers, letting food fall out of mouth, hands & all over the floor, ficking food??

O&M - help, we are having a big burst of motor development, but not really in cognitive or communication so O&M for the cognitively low functioning

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6. I particularly like these things about P. S. NEWS!!! [redacted]

The articles by Kate. I don't know how the people at P.S. news! always know just what to write about, just when I need it! I also get good resources and info. from the classified section

[redacted]

7. Additional comments you may have concerning P. S. NEWS III Keep it going! Its very helpful and informative. Sometimes, when you have a child who is dual sensory impaired, multi-handicapped, you feel very isolated. Even from parents of childrem with other types of disabilities. P.S. News! come every month, and helps me to know yes, there [redacted] is somebody out there [redacted] knows [redacted] we live. [redacted] this ne[redacted] the [redacted] I know. [redacted]omebody is [redacted] there!

Fold along dotted lines, staple or tape, stamp, and return.

[redacted]

Please return this completed survey to:
Kate Moss, Family Training Coordinator
Texas School for the Blind & Visually Impaired
Outreach Department
[redacted]

TSBVI - Outreach Dept.
1100 West 45th Street
Austin, Texas 78756

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Ain't Misbehavin':
Strategies for Improving the Lives of Students who are Deaf-Blind and Present Challenging Behavior

This 16 minute videotape provides people involved in the lives of individuals who are deaf-blind with practical strategies for proactively avoiding interactions which challenge relationships. It is valuable to families, educators, educational support staff, in-home and residential support providers, friends and community members, and anyone else who regularly interacts with a student who is deaf-blind. The video examines the crucial links between behavior and the issues of communication, control, and quality of life.

Initially, this presentation helps the viewer understand some of the reasons why children and youth who are deaf-blind may behave in ways caregivers find undesirable. An explanation of how behavior might be a way for the child to cope with unpredictable events and situations is illustrated. The videotape then describes how some troubling behaviors may be effective strategies children learn when other, more desirable ways to communicate aren't developed. Also discussed is the occurrence of challenging behavior as a response to situations over which a child has very little control, and finds unacceptable.

Explanations for the motivation behind some behaviors are followed by illustrations of concrete strategies that can help prevent undesirable behavior and improve relationships. Strategies for introducing structure, routine, and predictability into the child's life are shown. The videotape then demonstrates methods by which preferred communication can be taught as an alternative to troubling behavior. Issues of control, quality of life, and strategies for teaching choice-making are also explained.

Ain't Misbehavin' was developed and produced by the Deaf-Blind Outreach Department at Texas School for the Blind and Visually Impaired. The discussion is easy to understand and not technical. Video examples help the viewer gain a better understanding of the principles discussed. A copy of the script, and a bibliography of additional books, articles, and video resources accompany the video and are available in braille upon request.

Ain't Misbehavin' can be previewed by contacting Deaf-Blind Outreach, and may be duplicated in its entirety. To obtain a copy of this videotape, the text, and bibliography, send a blank VHS tape (30 minutes, minimum) to the Deaf-Blind Outreach Project, and request ***Ain't Misbehavin'***. Specify open captioned if preferred. The materials will be mailed free of charge.

Deaf-Blind Outreach Project
Texas School for the Blind and Visually Impaired
1100 West 45th Street
Austin, Texas 78756
(512)206-9103

Funding for the Deaf-Blind Project is provided by a Federal 34 CFR 307.11 grant. Funds are administered through the Texas Education Agency, Division of Special Education.

Ain't Misbehavin'

Strategies for Improving the Lives of Students who are Deaf-Blind and Present Challenging Behavior

Text of the Videotape

(Produced by Deaf-Blind Outreach, Texas School for the Blind and Visually Impaired)

A child with deaf-blindness may behave in ways that make others feel uncomfortable such as biting, crying, screaming, rocking, hand flapping, or throwing objects. These behaviors provide challenges to the people who interact with and care about the child, and may interfere with his inclusion into the mainstream of everyday life.

Decreasing challenging behavior begins by understanding why a child is behaving in this way. Behavior that is undesirable to others may be the way a child has learned to most effectively respond to a given situation or relationship. This behavior occurs because no other responses make sense to her. Those who care about the child may unknowingly even help bring about and encourage this behavior.

There are many reasons why a child may develop these behaviors. Here are three.

> First, the behavior may be a way for the child to cope with unpredictable events and situations.
>
> Second, the child may have learned that these behaviors are effective ways to communicate.
>
> Third, the behavior may be the child's response to what she perceives to be problems in the quality of her life. The child may be having difficulty participating in and enjoying life because of circumstances she finds unacceptable, and over which she has very little control.

Let's look at the first--at unpredictability. The world can be a very confusing place for a child with deaf-blindness. Limited vision and hearing, and few meaningful experiences reduce her knowledge about the world around her. Without this knowledge she has difficulty anticipating and understanding events.

For example, a child who is deaf-blind does not see or hear adults preparing a meal. She does not hear the rattle of pots and pans, see the table being set or notice when food is placed on it. When an adult comes to pick up and move her, she has no way to anticipate where she is going or why. Even if the child enjoys mealtime, she may hit, pinch, scratch or resist from fear and anxiety about not knowing what is happening. Her behavior is a way of coping with this unpredictability and confusion.

Another way to cope with unfamiliar events is by avoiding them completely. Many children with disabilities such as deaf-blindness are hesitant to handle objects or interact with others. They may seem withdrawn or passive, dropping things handed to them, or turning away from human contact. They have not learned that interactions with objects and people can be enjoyable, and may perceive the unknown to be threatening.

Funding for the Deaf-Blind Project is provided by a Federal 34 CFR 307.11 grant. Total funds equal $364,000 and are administered through the Texas Education Agency, Division of Special Education.

In unpredictable situations, as well as at other times, some children may develop patterns of repetitive behavior such as finger flicking, eye poking or rocking, that seem to serve no purpose and look strange to others. A child who is anxious and doesn't know what else to do may be comforted by the repetition of these familiar actions.

The second reason a child may demonstrate troubling behavior is that these actions are a learned way to communicate. A child may learn he can get attention by biting himself if adults always come, whether to protect or even to punish him for the behavior. A child who has objects taken away when he throws them may learn to reject things and end activities by throwing. The child has been taught that these behaviors effectively make desired things happen.

Children who are deaf-blind often have limited ways to spontaneously communicate with others. Communication forms most people use--such as speech, signs, gestures, points, or signals--may be difficult for someone with deaf-blindness. As a result, children with deaf-blindness provide people with fewer opportunities to respond to and reinforce these more socially acceptable forms of communication. Responses to undesired communication, such as self-abuse or throwing things, often only strengthen these behaviors.

A third reason children may sometimes behave in ways that other people don't like has to do with their quality of life. Children who are deaf-blind have the same needs as all human beings for a satisfying and enjoyable life. These include physical well-being, a sense of safety and security, and meaningful relationships. Control and influence in predictable environments and access to a variety of interesting and enjoyable activities are also important. A child with deaf-blindness often has limited ways to communicate about these needs and bring about changes when needs are not met. As a result, the appearance of behaviors like biting or hitting may be the only way we become aware that the child is unhappy.

For example, a child with deaf-blindness may communicate about the pain of a middle ear infection by banging his head. He may spit out food to communicate frustration at having little or no control over what he is eating. He may bite an adult in situations he sees as unfair. Improving the quality of a child's life may help prevent the occurrence of some of this undesired behavior.

Children with multiple disabilities are more likely than most to have physical problems like poor digestion and elimination, disturbed sleep, and chronic pain. They are less likely to have friendships and access to their favorite things. All of this influences their acceptance or tolerance of people and daily activities. Think of how you behave when faced with a rough day at work after two sleepless nights! How would you handle a string of disappointments without a friend to talk to?

Understanding why a child behaves in ways that appear inappropriate is an important first step in finding possible solutions.

When the behavior is a response to an unpredictable or unfamiliar world, the best solution is to provide more familiarity and predictability. We all use routines in our lives in a variety of ways. There are routine ways that we accomplish particular activities such as bathing, dressing, and eating breakfast. An entire day has a predictable routine to it as we dress, eat breakfast, then go about our work. A week has a predictable order with five days of work and a two day weekend. We need to consider all types of routines when working with a child who is deaf-blind.

Those who care about a child can help her cope by developing structure and routine in her life, and assuring that communication is clear and understandable. Routines are designed with clear, consistent beginnings and endings, while other aspects also remain constant. These include an activity's location, its sequence of steps, the materials used, the people involved, their actions, and the child's expected role. This sameness helps develop anticipation and expectations about what will happen and when.

Daily activities should flow in a predictable way. A child who is deaf-blind can learn that a trip to the bathroom for tooth brushing after meals is always followed by an enjoyable play activity. Knowing this, he might be more likely to move from eating to brushing teeth to play without behaving in undesirable ways.

New activities are best introduced when they contain as much familiar information as possible. For example, a student should learn a towel delivery routine with one adult before practicing it with a different instructor. New information is more easily learned when presented in the context of familiar routines.

A child who is deaf-blind may need concrete communication to better understand situations. One way to do this is by showing the child an object used in a familiar activity before beginning that activity. Another way is by giving specific touch cues to signal your expectations for the child's participation.

For example, to help a child anticipate being moved to the dinner table, give him a spoon, or some other object he will use during the meal, before taking him there; or if he is expected to lift a leg while dressing, touch the back of his calf to indicate that expectation.

When a child's day is filled with predictable events and he is associating objects with those events, a calendar box or anticipation shelf system can be established for him. The calendar box serves as a concrete reminder about the order of daily activities. When objects associated with activities are placed in a left to right sequence, they can represent the order of activities in the child's day. After an object is shown to the child, and then used in the activity, it is put back in its place and covered with a cloth or placed in a special location to communicate and demonstrate in a concrete way that the activity is finished.

Once this form of communication is established, variety and change in the child's daily routine can be explained meaningfully. Pictures, tactile symbols, print or Braille may replace objects when and if the child develops the ability to understand these more abstract forms of communication.

If it appears that the child is using troubling behavior to communicate, teaching more appropriate expressive communication skills can help replace inappropriate behavior. Children with deaf-blindness will communicate with us. It's our responsibility to understand what they are trying to say, then teach them how to communicate in ways that are more acceptable and understandable to others.

When undesired behaviors don't produce the expected results for the child, their power as communication is decreased. By modeling, shaping, prompting and reinforcing, we help a child learn more preferred ways to communicate. For example, a child who throws unwanted materials may not know another way to reject them. He can be systematically taught to gently push the materials to one side. If he begins throwing, that action can be redirected to a push. It is important to reinforce the push and not the throw.

It is also important to honor a child's rejection instead of punishing it. We should teach an appropriate way to communicate "I don't want," as well as "I want," then acknowledge and respond to that message. Communication is measured by a person's ability to clearly and successfully express needs, preferences and desires.

Allowing a child to make choices is an important way to decrease the likelihood that troubling behavior will occur. Children who are deaf-blind frequently have choices made for them. They're not allowed to choose the clothes they wear, the food they eat or the order in which it's eaten. They aren't given opportunities to select their daily activities or friends. This lack of choice decreases a child's power to control his or her own life. Socially inappropriate behavior may result as the child attempts to gain some control.

When a child has difficulty expressing choices, options can be offered very concretely. Present two materials to the child. He may reach for what he wants. Or, if one option is rejected, the other can be interpreted as his choice. In this way control can be experienced. Opportunities for making choices should be provided throughout the day. As a child becomes more accustomed to making choices, he may be able to do this more independently.

Often a child with deaf-blindness interacts with the world in limited ways. It can be difficult finding interesting and meaningful things for her to do. However, if she is not actively engaged in these kinds of activities, time will more likely be filled with behavior that others find unacceptable. As the quality of a child's life improves, and her days are filled with more feelings of security and control, more enjoyable activities and meaningful relationships, we can expect this undesirable behavior to decrease.

In summary, to help prevent the occurrence of undesired behaviors:

1) provide a predictable environment for the child;
2) redirect undesirable behavior and always teach the child alternative desirable communication to be used in its place;
3) provide and maintain a high quality of life for the child.

By creating a secure, predictable and enjoyable environment, it is easier and fairer for everyone to prevent troubling behaviors from happening in the first place, rather than reacting to them after they occur.

•

"I've come to a frightening conclusion that I am the decisive element in the classroom. It's my personal approach that creates the climate. It's my daily mood that makes the weather. As a teacher, I possess a tremendous power to make a child's life miserable or joyous. I can be a tool of torture or an instrument of inspiration. I can humiliate or humor, hurt or heal. In all situations it is my response that decides whether a crisis will be escalated or de-escalated and a child humanized or dehumanized."

Haim Ginott, child psychologist and teacher

Ain't Misbehavin':
Strategies for Improving the Lives of Students who are Deaf-Blind and Present Challenging Behavior

As of September 30, 1995, a total of 160 copies of *Ain't Misbehavin'* have been distributed to 37 states and 3 foreign countries. Because recipients are encouraged to freely copy and share the tape, an undetermined number of additional videotapes are being used nationwide. Deaf-Blind Outreach at Texas School for the Blind and Visually Impaired has sent videotapes to:

USA
Alaska
Arizona
Arkansas
California
Connecticut
Florida
Georgia
Idaho
Illinois
Indiana
Iowa
Kansas
Kentucky
Louisiana
Maryland
Massachusetts
Michigan
Minnesota
Mississippi
Missouri
Montana
Nebraska
Nevada
New Mexico
New York
North Dakota
Ohio
Oklahoma
Oregon
Pennsylvania
South Carolina
Texas
Utah
Vermont
West Virginia
Wisconsin
Wyoming

Canada
Alberta
British Columbia
Newfoundland
Nova Scotia
Ontario
Saskatchewan

England
Spain

INFORMATION PAGES:

For People Involved in the Lives of Individuals with Deaf-Blindness

Answers to Questions Commonly Asked by Families, Professionals, and Members of the Community.

1. Understanding Deaf-Blindness
2. Communication for Individuals with Deaf-Blindness
3. Behavior Interventions for Individuals with Deaf-Blindness
4. Environmental Modifications for People with Deaf-Blindness
5. Active Participation for Individuals with Deaf-Blindness
6. Resources for Further Information on Deaf-Blindness

Developed by David Wiley,
Deaf-Blind Outreach, Texas School for the Blind and Visually Impaired

for the Interagency Task Force for Future Services to Deaf-Blind

These information pages provide a very basic answers to questions asked by people who know someone who is deaf-blind. You may find them helpful if you have a family member, neighbor, coworker, client, or customer who has both a vision and a hearing impairment. The information applies to all individuals with deaf-blindness, including those with additional severe disabilities. Of course each individual is unique, so people using these fact sheets will have to apply the information in different ways.

This packet is only the first step in helping you interact with, understand, and support people who are deaf-blind. It will not provide a thorough understanding of deaf-blindness, but it may help you know what questions to ask. The materials, organizations, and people listed in the final information page can provide more in-depth information.

(Revised 5/95)

Deaf-Blind Outreach at Texas School for the Blind and Visually Impaired is supported by a Federal CFR 307.11 grant. Total funds equal $364,000 and are administered through the Texas Education Agency, Division of Special Education.

Understanding Deaf-Blindness: The combination of vision and hearing impairments.

#1

What is Deaf-Blindness?

Deaf-blindness refers to the combination of both a vision and a hearing impairment. The severity of the vision and hearing loss may vary among individuals who are considered deaf-blind. Most people who are deaf-blind have some functional use of either their vision, hearing, or both. However, even relatively mild sensory impairments require significant special considerations when they occur together.

Deaf-blindness may be a result of genetic abnormalities, illness, pre-mature birth, pre-natal infection, or injury. Some common causes are Usher's Syndrome, Congenital Rubella Syndrome, CMV, and CHARGE Association, among many others. The latter three listed here are often associated with some degree of cognitive impairment and additional disabilities.

There are a significant number of Texans with deaf-blindness. An accurate total for all ages is not available. In 1995 there were 594 students who were registered as deaf-blind in public schools.

Why are special considerations for deaf-blindness important when interacting, developing programs, and arranging the environment?

The combined effects of vision and hearing losses together are much more significant than simply the addition of the effects of blindness and deafness when they occur separately. Vision and hearing are the distance senses--those which allow a person to get information from beyond arms' reach. In many cases adaptations for sensory impairments substitute one distance sense for another: vision for hearing, or hearing for vision. The presence of both these impairments together leaves an individual with no reliable distance senses and requires additional and different accommodations. People with deaf-blindness often have more difficulty communicating; trusting and bonding with others; gaining information incidentally through the environment; moving freely though the environment; and anticipating events.

What impact does deaf-blindness have on the ability to receive information?

It is important to consider the amount of information inaccessible to a person with deaf-blindness. People with no sensory impairments get information through observation. They learn by watching and listening to what happens around them. What they see and hear lets them know what is happening, what to expect, and what other people expect of them. This information is absent or unclear for a person with deaf-blindness. The information most people naturally pick up must be carefully provided in a way that the person who is deaf-blind can understand. Aside from information deliberately supplied by others, someone who is deaf-blind primarily learns things by exploring with touch. Consider everything the average person knows that no one has specifically told him and with which he has no hands on experience. This is all information a person with deaf-blindness may have missed.

How does deaf-blindness affect the strategies employed by caregivers?

Intervention strategies may be used inappropriately when the professionals developing them are unfamiliar with the implications of deaf-blindness. For example, lack of information may be misinterpreted as an inability to understand or cooperate. Special communication strategies, environmental modifications, and the use of consistent routines may help provide this information and make the world less confusing to individuals who are deaf-blind. These strategies may result in an individual being able to independently complete tasks that people may have felt he was unable or unwilling to do.

What it is like to be deaf-blind?

One of the best ways to learn more about deaf-blindness is through simulation. People who provide support to someone who is deaf-blind should try to go through a day completing ordinary tasks without using vision or hearing. Expensive simulators are available, but a blindfold and ear plugs can provide some understanding of the effects of deaf-blindness. By discovering how sensory impairments reduce the information available and cause feelings of isolation and apprehension, concerned people can know more about how to assist someone who is deaf-blind. Simulation also shows how important it is for someone who is deaf-blind to trust the people around him.

Is more information on deaf-blindness available?

To learn more about deaf-blindness and its implications, make use of the resources listed on Information Page #6 in this series. If you do not have this list, contact:

David Wiley; Deaf-Blind Outreach; Texas School for the Blind and Visually Impaired;
1100 W. 45th; Austin, TX 78756; (512)206-9219.

(rev. 5/95)

Communication for Individuals with Deaf-Blindness: #2

How do people who are deaf-blind communicate?

The strategies used by people who are deaf-blind and their communication partners vary widely. Individuals who have both a visual and a hearing impairment often employ unique communication systems. In most cases, these systems can be expanded and shaped so the person develops more communication strategies. Additional strategies may allow the person to understand and be understood by a wider group of communication partners. However, those motivated to meaningfully communicate with a person who is deaf-blind must have flexibility and a willingness to learn the specifics of that person's system.

Everyone uses a variety of forms of communication. In an interaction, any person might speak, gesture, point, hold up an object, draw a diagram, and pat someone on the shoulder. All of these actions contribute to her message. An individual who is deaf-blind may also use a number of different forms of communication. Each person is able to use and understand a different combination of these forms. They might include speech, sign language, tactile sign language, print, braille, pictures, tactile symbols, gestures, objects, physical touch, movement, and signals. There may be some forms of communication a person understands when others use them, even if she does not use them to express herself.

How does a caregiver know which form of communication to use?

The use of consistent routines, touch cues, and repetitive movements by caregivers might be the first way a child who is deaf-blind learns that actions and objects can have meaning. A caregiver who reacts consistently to a child's signals will help the child learn that her actions can influence what other people do. As the child understands this better, caregivers can begin to use objects to represent actions and routines, such as a spoon representing meal time, or a towel representing a bath. When that is understood, more abstract forms such as parts of objects or pictures, and eventually sign language, can be taught and used.

This process of acquiring new communication forms may take years for some people who are deaf-blind, so it should not be rushed. Some people who have severe disabilities in addition to deaf-blindness never learn more abstract communication, and continue to rely on basic forms such as gestures and objects throughout their lives. Communication partners should be careful to speak to the person on her own level by using forms of communication she understands. When trying to teach new language skills, caregivers should not over use more difficult communication forms, as this may only confuse and frustrate the individual who is deaf-blind. New communication forms should always be paired with a familiar form.

Caregivers with no prior knowledge of an individual may be able to find out how she communicates by asking her using speech or sign. If the person doesn't understand, or is unable to respond, information about how to communicate can be learned from others who know the person or past records. If no other information is available, a caregiver should try a variety of messages in several contexts using various communication forms. Observe the individual to see what she appears to understand and take note of the ways she expresses herself.

Why is a calendar important for a person who is deaf-blind?

Because people with deaf-blindness receive less information about what is happening, they have difficulty anticipating events and knowing what to do next. They may be forced to wait patiently until told what to do, with every activity being a surprise. This often results in a person losing her initiative, becoming apprehensive, or resisting. Transitions from one activity to another become difficult. When a person doesn't know what to expect, she experiences no feeling of control about the things that happen.

Calendars are a way to inform a person who is deaf-blind about the events that she should expect. They also provide her with the opportunity to influence those events. Calendars can take many forms, based on the person's level of understanding. A simple shelf where an object is placed to represent the next activity, or an elaborate datebook with activities scheduled for months in advance can both serve as calendars.

A calendar helps a person anticipate what is to come, and remember her agenda. The calendar also provides a way for someone with deaf-blindness to talk about past and future events. These discussions help others understand what the person likes, so she can have more influence over her daily activities and the important issues in her life.

How do trust and bonding affect communication with people who are deaf-blind?

The first communication attempts by many people who are deaf-blind may have been subtle and hard to recognize. As a result, these people may have had early experiences of having their communication attempts ignored or misunderstood. Because communication is difficult, they may have been led through their days without anyone attempting to inform them of what to expect. The message "come with me" might have meant a trip for ice cream or a dental appointment. Consequently, an individual who is deaf-blind often may become distrustful of communication partners. This problem continues when large numbers of professionals work briefly with the individual, having no opportunity to learn her unique communication strategies. These factors contribute to further limiting the person's skills and motivation to communicate. To overcome this, individuals with deaf-blindness need an opportunity to form consistent trusting relationships with attentive communication partners.

How does communication relate to troubling behavior?

For individuals who are deaf-blind, there is a link between communication and challenging behaviors such as self-abuse and aggression. These behaviors may have begun as the most reliable way for a person with deaf-blindness to get her point across. Such behaviors might also be expected expressions of frustration at not being able to call upon reliable communication when needs are not being met. The problem may also stem from anxiety caused by confusion over what is happening and what is to be expected. Most often caregivers can best approach troubling behaviors by treating them as communication attempts, and reduce them by teaching alternative communication strategies.

Providing predictable routines and more information about what to anticipate often reduces anxiety and associated behavior problems. Teaching appropriate ways to seek assistance, make requests, and indicate rejection also helps. As the person successfully uses these strategies, she can decrease reliance on inappropriate ways to communicate. (rev. 2/95)

Behavior Interventions for Individuals with Deaf-Blindness

#3

How are a person's deaf-blindness and challenging behavior be related?

Troubling behavior is often the result of a person's impaired ability to interact with the world. Some individuals who are deaf-blind may develop behaviors such as uncooperativeness, aggression, or self abuse, in trying to make sense of confusing situations they don't know how to communicate about or change. These behaviors might be ways for a person to cope with unpredictable events and situations. They may be effective strategies a person has learned to use when other, more desirable ways to communicate aren't developed. The behavior may be a response to situations which a person find unacceptable and over which she has very little control. In situations such as these, behavior problems may relate directly to deaf-blindness and associated problems in gathering information and communicating. Effective behavioral change will result from efforts to understand and respond to the cause of a behavior, not just the behavior itself.

How can providing more information reduce behavior problems?

When someone gets incomplete or inaccurate information about the world, events in her life may seem like a continuous series of surprises. An individual who is deaf-blind misses significant information about what is happening to and around her. As a result, she can easily begin to feel isolated, frustrated, threatened, or confused. Some aggressive behaviors may be an effort by the individual to protect herself when she is unsure of the situation. Some self-abusive behaviors may be expected expressions of anxiety or frustration. Actions that may be attributed to a lack of cooperation may instead be due to incomplete information about what is expected and why. When caregivers develop strategies for giving more meaningful information about the world to a person who is deaf-blind, troubling behaviors related to these motavations should decrease.

Introducing structure, routine, and predictability into the person's life is one way to supply this information. Predictable routines and familiar activities help people know what to expect. Using consistent communication strategies based on the ability of the person to understand is also important. Supporting communication by using concrete communication forms such as objects, pictures, tactiles symbols, or calendars also reinforces the person's expectations. Providing information using more than one communication form makes messages more clear and understandable. These strategies help a person with deaf-blindness know what to anticipate. By informing a person what to anticipate, anxiety and behavior problems will often decrease as more trust is developed.

How can teaching communication strategies reduce behavior problems?

Some troubling behaviors may be effective strategies a person has learned to communicate things she has no other way to say. This behavior may have begun as the most reliable way for a person to make changes occur when she was unhappy. The person may not know another way to say that she needs something, that she doesn't like something, that she is tired, or that she doesn't feel well. Often the best approach to reducing troubling behaviors is to treat them as communication attempts, and teach alternative strategies for expressing these ideas.

A person who is deaf-blind can be taught more appropriate communication as an alternative to troubling behavior. As the person learns to appropriately seek assistance, make requests, and indicate rejection, she can decrease reliance on more inappropriate ways to communicate. These communication strategies can assist the person in making and expressing choices, enabling the person have a greater sence of control about the activities of her life.

How does quality of life relate to communication and behavior?

People sometimes become depressed, frustrated, or angry when they are not satisfied with their lifestyles. They feel these emotions, for instance, when they are troubled about problems with their homes, interpersonal relationships, jobs, or health. Such feelings may also accompany loneliness, loss of a loved one, or lack of enjoyment in someone's life. Often these feelings are often difficult to express even for people without communication problems. When people with deaf-blindness have no strategies to discuss abstract issues, they may find it impossible to clearly express what they think is wrong in their lives, and how it affects the way they feel. As a result, the appearance of behaviors like biting or hitting may be the only way others find out they are unhappy.

For example, a person with deaf-blindness may communicate about the pain of a middle ear infection by banging his head. He may spit out food to communicate frustration at having little or no control over what he is eating. He may bite an adult in situations he sees as unfair. Children with multiple disabilities are more likely than most to have physical problems like poor digestion, disturbed sleep, and chronic pain. They are less likely to have friendships, control, and access to their favorite things. All of this influences the way they respond to people and daily activities.

If a person with deaf-blindness is behaving in troubling ways, it is important that those who care about her examine and work to improve the quality of her life. People want to be physically comfortable, safe, and secure. They want to be surrounded by people they like. They want to know there are people and things they can trust. They want to do a variety of meaningful and enjoyable things, and have influence over what happens in their lives. Caregivers should consider how this person feels about the circumstances of her own life, and not how the caregiver thinks she ought to feel. Every person decides for herself what is important, what brings joy, and what causes unhappiness. Helping people have what they consider to be safe, comfortable, and satisfying lifestyles is essential for reducung problem behaviors related to negative feelings about quality of life. (rev. 5/95)

Environmental Modifications for Individuals with Deaf-Blindness: #4

Do people who are deaf-blind need special places?

People with deaf-blindness do not need separate and very different environments in which to live, work, and enjoy themselves. They generally share the same homes, workplaces, and recreational facilities with their neighbors and friends who are sighted and hearing. However, there are some simple modifications for any environment that can help a person who is deaf-blind to be more comfortable and independent. These modifications are fair and reasonable accommodations to make spaces, objects, and information more accessible, as well as providing a greater sense of security and reducing frustration.

How can the environment be modified to make things easier for someone who is deaf-blind?

Simplifying the environment is a good first step to making it more accessible for someone who is deaf-blind. Reducing clutter on the floor, tables, countertops, and in drawers makes the environment much easier to understand. People who have deaf-blindness often have more difficulty or need additional time in finding their way, or locating things. A cluttered environment adds to the problem. For example, if the silverware drawer also includes extra miscellaneous items, it is much more difficult for someone who is deaf-blind to locate a fork. A room that is totally full and disorderly is very difficult to walk though.

Keeping clear routes through any space is important. Individuals who are deaf-blind find it easiest to get from one place to another by following large even surfaces such as walls, counters, or railings. Caregivers should help the person who is deaf-blind discover the best route to move toward regular destinations. They should then remove potential obstacles, help the person become familiar and comfortable with each route, and make sure the paths stay clear.

Placing related items near one another also makes activities simpler. For instance, storing the bread beside the toaster makes a quick breakfast far less complicated. Placing all necessary materials on one shelf beside the work station improves efficiency and independence on the job. Materials should also be stored consistently. An individual with deaf-blindness is much more independent when items can always be found in the same place.

Why are consistency and routine in the environment so important?

People with dual sensory impairments have difficulty receiving information about the environment around them from a distance. Changes that might seem inconsequential to someone with no sensory impairments can make things confusing and threatening to someone who is unable to easily detect them. This often reduces a person's ability to independently move through rooms and find materials, increasing the need for assistance during otherwise simple activities.

It is extremely important that changes in the environment be kept to a minimum, and that any changes that are made be shown and explained to the person who is deaf-blind. Obviously, rearranging furniture can make spaces totally confusing. But it might be equally confusing to add a coat rack, or hang a picture on a wall that someone routinely follows out of a room. Even floor coverings are used as cues to help recognize and locate areas in an environment. Changing the carpet or tile, or resurfacing the driveway should be done with this in mind. Changes that can't be avoided should be shown and explained to a person who is deaf-blind.

Furthermore, adding new hanging plants, shelves on the wall, or throw rugs can result in a serious safety risk. In addition to injury, surprising new features in the environment may result in making a person who is deaf-blind feel less secure about moving through the environment independently. Each time someone trips over a new magazine rack, or unexpectedly encounters a new clothes line, he may become less willing to move about without assistance.

Why is the way things look and sound important?

It is equally important to reduce visual and auditory "clutter", so a person who is deaf-blind can make better use of any vision and hearing she may have. People with sensory impairments may have difficulty separating important visual and auditory cues from the background. For example, if someone using sign language is wearing a shirt with a colorful and busy pattern, his signs will be much more difficult to see. The same problem may be present with patterned wallpaper or curtains. Backgrounds covered with numerous objects or pictures may be visually confusing. Simplifying visual backgrounds and removing unneeded materials helps people with low vision find and concentrate on what needs to be viewed.

Another factor to consider for someone with low vision is lighting. Low light and shadows may make seeing things very difficult. Bright glares may cause similar visual difficulties. Creating environments that have good light without glare is a good start, but some experimentation may be necessary to find the ideal lighting for each individual.

When someone relies on auditory cues, but is hearing impaired, background noise can be a problem. Reducing noise or relocating sources of noise can help. For instance, a noisy fan can be placed on the other side of the room from a person's work station or dining area. When noise sources can not be changed, the environment might be engineered so the person who is hearing impaired is less affected by them. An example might be letting a person move to a bedroom farther away from the central air conditioner.

What modified materials would be helpful?

Items in the environment should be modified based on individual need, rather than general rules. Individuals who can not hear, but have a functional use of vision may find it useful to have fire alarms and door bells wired to flashing lights. Those who are using their vision might also find it helpful for spaces and materials to have clearly contrasting colors and well defined borders. Those who are unable to see, might take advantage of textured surfaces to identify locations and materials. Pens that make raised lines can be used to mark items like washer and dryer dials, to make them easier to use independently. There are many adaptive aids and devices that might help. The resources listed on page #6 can provide further information.

(rev. 2/95)

Active Participation for Individuals with Deaf-Blindness

#5

What can a person with deaf-blindness do?

Of course this question has as many answers as there are people who are deaf-blind. Every person with deaf-blindness has his own skills and interests. There are no activities that are particularly suited for someone who is deaf-blind. Supporting a person to participate in a variety of meaningful, productive, and interesting activities begins by assessing and utilizing: the abilities and preferences of the person; the routines and activities found in the environments the person encounters; and the needs and interests of the people with whom the person regularly interacts.

Some people with deaf-blindness learn to complete most tasks independently. Others, especially those with additional disabilities, need varying amounts of assistance in order to participate in activities. Even if a person does not have the skills to complete a task or activity in its entirety, he may be able to complete a portion or step of the activity and team with someone else who can complete the other steps. This is called partial participation. An example or partial participation might be someone who can not cook a meal, but can toss the salad or slice the bread. Some people may need physical assistance to complete any portion of an activity. This is called co-active participation. Support through partial and co-active participation allows a person to engage in a wide variety of activities, even if he is not independent.

Why is active participation so important for helping someone with deaf-blindness learn?

When a young child has deaf-blindness, he is less motavated to explore the world. He does not perceive all the environmental cues which lead people to become curious about objects and places around them. Consequently, he may learn fewer lessons about the properties of objects and space. Passive stimulation does not develop a person's concepts and capabilities like active participation in learning. Caregivers should provide safe, accessable, and consistent places for a child to spend some time actively exploring and learning these basic concepts. This will provide a better foundation as the child gets older and starts to learn skills and participate in activities.

People who are deaf-blind learn by doing. Most people learn better when they have an opportunity to learn by experience, but for someone with deaf-blindness experience is a necessity. The use of observation and modeling are not effective teaching strategies when the learner has sensory impairments. Watching a friend or classmate participate in an activity may not be an effective way to learn even if a visually impaired person can functionally use his vision in some circumstances. Learning new information visually is much more complicated than recognizing familiar situations. Furthermore, because communication is often a weakness for people who are deaf-blind, explanation using formal language is not a very effective teaching strategy. Words and signs are not meaningful unless an individual associates them with experiences they have had. Lessons should be experienially based.

Wouldn't a person with deaf-blindness be happier if other people took care of him?

Everyone needs the opportunity to feel good about himself and to make contributions to the world around him. Everyone enjoys the feeling of being competent and accomplishing something. People who are deaf-blind are often excluded from these opportunities. It is important the these individuals learn skills in which they feel confident, and that they have a chance to use these skills to gain a sense of belongingness and respect from the people with whom they interact. Such opportunities to make meaningful contributions are are important, even if a person requires adaptations and support to participate.

What if the person objects when asked to participate?

Routines are very important to everyone. Because people who are deaf-blind receive less information about the world around them, routines take on even greater significance. If a person has not been allowed or encouraged to participate in activities in the past, his routine is to stay uninvolved. Non-participation can become a habit, just like a cup of coffee in the morning or an evening walk. Any time these routines are disrupted, it is natural to feel a sense of resistance.

A fuller activity schedule is often rejected be someone who has not had the opportunity to participate very often. New chores may result in troubling behavior for these individuals.

Shouldn't everyone have free time?

Everyone needs a chance to recharge their batteries by resting and participating in enjoyable pastimes. Most people have a repertoire of activities they look forward to doing, and are anxious for a chance when they are free to do them. However, many people who are deaf-blind do not have self-directed activities they can readily call upon when presented with free time.

(rev. 2/95)

Resources for Further Information on Deaf-Blindness

#6

To gain more skill and knowledge about deaf-blindness, you may contact:

The Interagency Task Force for Future Services to Deaf-Blind has representatives from the organizations list below, as well as: Texas Deaf-Blind Association; Texas Department of Health; Texas Commission for the Deaf and Hearing Impaired; Texas Education Agency; and Texas Department of Human Services. The Task Force can be contacted in care of the Texas Commission for the Blind or Deaf-Blind Multihandicapped Association of Texas at the addresses listed below.

The following Task Force representatives provide services, training, information and referral directly related to persons with deaf-blindness:

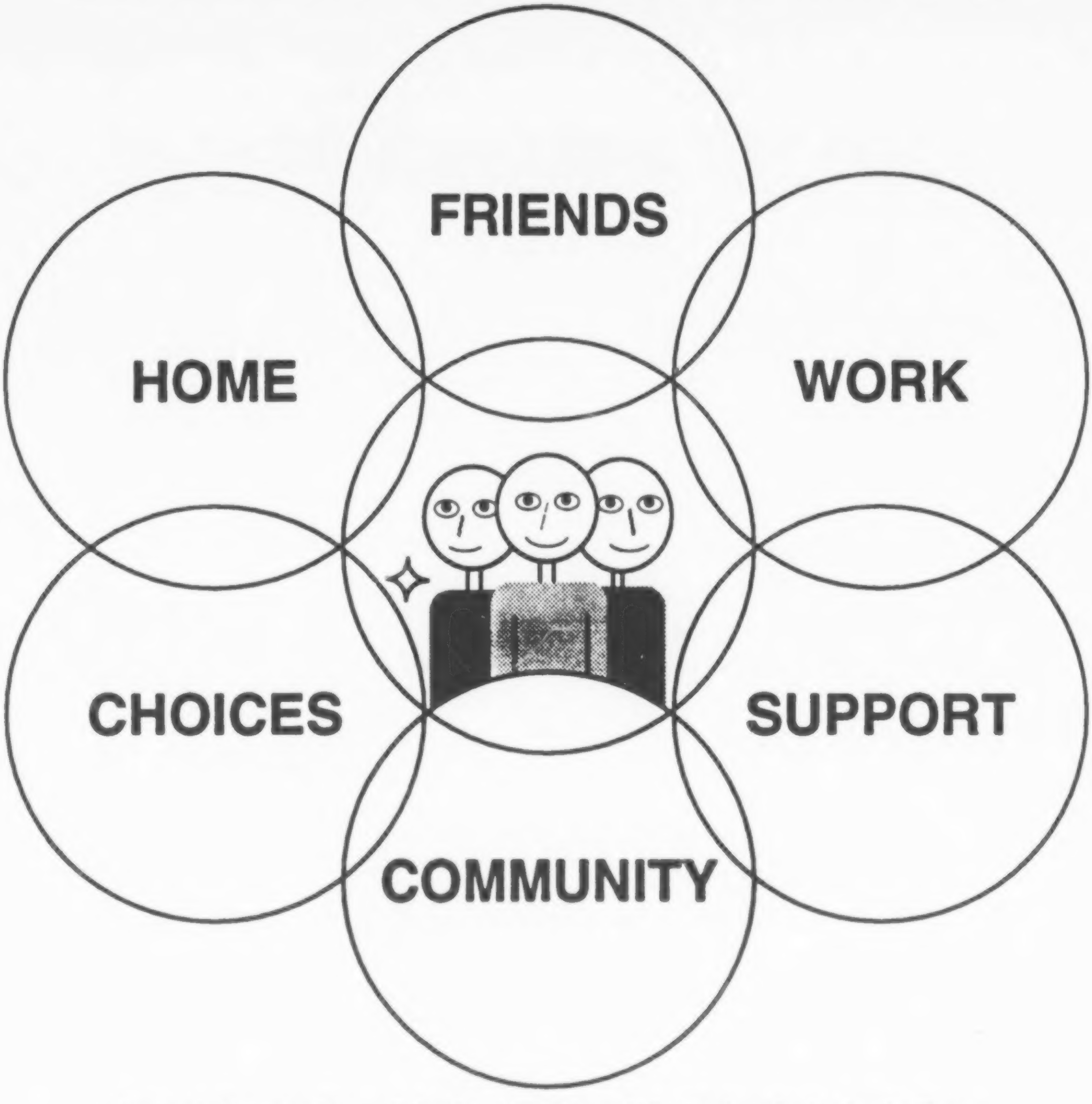
Deaf-Blind Outreach Texas School for the Blind and Visually Impaired 1100 W. 45th Street Austin, TX 78756 (512) 454-8631 x103	Training for professionals and families involved with school-aged individuals who are deaf-blind, 0-22 years. Workshops, on-site consultation, information and referral services. Mailing list for newsletter and workshop announcements.
Deaf-Blind Services Texas Commission for the Blind 4800 N. Lamar Austin, TX 78756 (512) 459-2575	Training, support, and information on employment and independent living issues for deaf-blind adults. Information and support for families of children who are deaf-blind. Apartment living program.
Deaf-Blind Multihandicapped Services Texas Rehabilitation Commission 4900 N. Lamar Austin, TX 78751 (512) 483-4185	Residential support and an array of services offered through Medicaid waiver dedicated to individuals who are deaf-blind and multiply disabled, age 18 and over. Group homes and in-home support.
Regional Representative Helen Keller National Center 4455 LBJ Freeway, LB #3 Suite 517 Dallas, TX 75244 (214)490-9677	Information, referral, and training for adult service agencies, families, and individuals who are deaf-blind.
The Deaf-Blind Multihandicapped Assn. of Texas 815 High School Dr. Seagoville, TX 75159 (214)287-1904	Family support, advocacy, training, information, and referral for all persons interested in issues related to deaf-blindness.
Physical Management Division Tex. Dept. of Mental Health & Mental Retardation P.O. Box 12688 Austin, TX 78751	Training and support for professionals and staff working with individuals who are deaf-blind being served by TDMHMR and Community MHMR Centers.

A Brief Guide to

PERSONAL FUTURES PLANNING

by
Kate Moss and David Wiley

ORGANIZING YOUR COMMUNITY TO ENVISION AND BUILD A DESIRABLE FUTURE WITH YOU.



Outreach Program, Texas School for the Blind and Visually Impaired – Austin, Texas

Funding for the Deaf-Blind Project is provided by a Federal 34 CFR 307.11 grant. Total funds equal $364, 000 and are administered through the Texas Education Agency, Division of Special Education.

5/95

A BRIEF GUIDE TO PERSONAL FUTURES PLANNING

by Kate Moss & David Wiley, Outreach Program, T.S.B.V.I.

A DIFFERENT WAY TO THINK ABOUT PLANNING

The Personal Futures Planning process is different than other kinds of planning you may have taken part in because of both the underlying philosophies and the methods employed. The differences can be seen in the focus, the identities of the people involved, the questions asked, and the level of follow-through. Consequently, the outcomes are often different, and hopefully more positive.

This process would be beneficial for anyone, young or old. The Outreach Program has been training facilitators to lead this process and create positive futures for individuals with deaf-blindness, and severe multiple disabilities. The fact that the process focuses on these individuals' capacities rather than their limitations, however, is only one way it may differ from more traditional planning.

THE FOCUS

Personal Futures Planning is different than most planning meetings for people with disabilities simply because it is voluntary for everyone involved. The meetings are not mandated by any law, and no one needs attend unless he or she wants. No participant is assigned anything to do during the meetings. Even though, hopefully, participants will be accomplishing great things individually and as a group, all action is voluntary.

Because no one is required to take part, there are no rules as such. Committed individuals form a group or "circle" that is self-governing. With the help of a facilitator, the group decides where, when, and how often to meet, as well as what the goals are. Personal Futures Planning is very flexible, and there are no forms to fill out. There are some guidelines that help make the process successful, however they are not specific. Any formula would limit the process, and take away from its diverse nature.

The focus is also different because planning is done *with* the individual and his or her family, instead of *for* them. Even when professionals consider their meetings student-, client-, or family-centered, these meetings usually take place on the professional's "turf". Generally they are held in intimidating offices or conference rooms and at times which make it difficult to get the entire family and other community members to gather. Agendas are often laid out in advance, to conform to a regulation or paperwork requirement.

Personal Futures Planning is done anywhere the group finds comfortable and convenient--someone's home, church, park, classroom, library, etc. The group picks a mutually workable time for meetings. It is an informal setting, often including snacks and some time to socialize. Participants usually find Personal Futures Planning to be fun and exciting, even though they are dealing with difficult and often emotional issues.

THE PARTICIPANTS

For most of us, friends and neighbors have a greater impact on our lives than bureaucracies. You may remember that you found your first job or apartment through family or neighborhood connections. Unfortunately, these powerful connections fail to develop or get severed for many people with disabilities. Planning and support is turned over to agency staff members who are often caring, but ultimately uninvolved.

Traditionally, planning by different groups is usually done in isolation. Families make plans at home. Schools and agencies plan in their respective buildings. Community clubs and organizations make plans at their own meetings, as do churches, neighborhood groups, and so on. Transition Planning for students nearing graduation is one step toward unified planning, but it is limited in time and scope. With Personal Futures Planning, all of the significant people influencing an individual's life sit down in the same room. Together with the individual they make decisions and plan appropriate actions as a unified group.

THE QUESTIONS

When employing the Personal Futures Planning philosophy, we start by asking, "What are this individual's preferences and strengths?" The focus is not his or her problems or disabilities. Instead of asking what we as professionals and family members feel the individual needs, we ask, "What does the individual want? What choices does he or she make? What things do we know work well from that person's perspective?" The participants in the process try to identify what the ideal situation might be in the person's future. They also identify obstacles that may stand in the way of reaching this person's unique ideal situation, and brainstorm ways to work around those barriers. Traditional planning methods most often lead us to describe the existing service options, and decide where a person might best fit. This results in a very limited number of "individualized" situations, stifling creativity, and making us settle for circumstances that are less than ideal. Personal Futures Planning gives us permission to dream.

THE FOLLOW-THROUGH

Personal Futures Planning is successful because the action taken is done in small and easily achieveable steps. Because the goals are not overwhelming, the group immediately achieves some success. As successes start to build, an air of excitement is created among group members. This leads them to dream ever bigger dreams. Momentum is maintained by the commitment of the group to meet fairly often to celebrate successes, reaffirm promising actions, and brainstorm new solutions for overcoming obstacles. Personal Futures Planning does not wait to see what the future holds. Personal Futures Planning actively creates a bright future for an individual by organizing and utilizing the energies of those who care most about that person.

THE BASIC STEPS OF AN EFFECTIVE PLANNING PROCESS

An effective planning process includes several basic steps. The design of a planning process that includes these steps is far more important than the details of each component. The greatest amount of quality change occurs in people's lives when:

1. *People begin with a clear and shared appraciation of the gifts and capacities of the focus person.*
2. *Committed people develop a common understanding of a specific positive future: a common dream.*
3. *Committed people agree to meet regularly to brainstorm and make commitments to act. These people are often those who spend a lot of time with the person or have known the person for a long time.*
4. *The group includes at least one person --- a family member, advocate, community member, staff person or the person who is the focus of the planning --- who is a* ***champion*** *of the dream. This person makes extraordinary efforts to bring the dream into reality.*
5. *At least one agency or community organization is committed to supporting the implementation of the plan.*

Taken from Making Futures Happen: A Manual for Facilitators of Personal Futures Planning by Beth Mount, published through the Minnesota Governor's Council on Developmental Disabilities, St. Paul, MN.

COMPONENTS OF THE PERSONAL FUTURES PLANNING PROCESS

1. **Getting started**: designing the planning process. A Personal Futures Planning facilitator works with the focus person, family, and others to determine:
   a. who should be involved in the planning process;
   b. how the process should be adapted to fit unique challenges and opportunities; and
   c. how to create the conditions, such as meeting location and time, that will make the plan most likely to succeed.

   This step may be done in person or over the phone prior to the development of the personal profile and the planning meeting.

2. **Telling stories**: building a personal profile. The facilitator meets with the person and those who know him or her the best among family, friends, and professionals to :
   a. build a description of the life story of the person, his or her capacities and preferences, opportunities available, and situations that may present challenges; and
   b. lay the groundwork for the planning meeting.

   This phase may take 2-3 hours and can be done separately or immediately before the next phase.

3. **Dreaming together**: the planning meeting. The facilitator assists the group who developed the personal profile and any additional interested people involved with the focus person to:
   a. consider the persons unique preferences, abilities, opportunities, and challenges while building a plan for the future; and
   b. make commitments for specific, small action steps to help make the dream a reality.

   This phase may take 2-3 hours and can be done separately or immediately after the personal profile phase. If done separately, additional people may join the group to take part in the planning meeting. If that is the case, the personal profile should be reviewed for the larger group, and any "maps" drawn should be available for all to see.

4. **Following through**: creating a future over time. The group meets regularly to:
   a. share accomplishments and review progress made on the action plan; and
   b. discover and commit to the next steps for action.

Adapted from Making Futures Happen: A Manual for Facilitators of Personal Futures Planning .

WHO IS IN THE GROUP?

Personal Futures Planning begins when a group of people and a Personal Futures Planning facilitator join together to focus on how to support one individual in creating and working toward dreams for a happy and meaningful life. The facilitator helps the group get organized and helps guide the discussion at meetings. People who know the focus person from a variety of different circumstances will be attending planning sessions. It is important that everyone to get to know and feel comfortable with one another. The first step of any Personal Futures Plan is learning from everyone who he or she is, and how he or she is connected to the focus person.

The group should include the individuals who have the most knowledge about the focus person and the community where the person lives. This would include the individual who is the focus of the planning process, family members (parents, siblings, grandparents, etc.), friends of the individual or family, community members who are knowledgeable about the individual and/or the resources available in the community (neighbors, ministers, civic leaders, co-workers, teachers, classmates, human service personnel, etc.), and other individuals who care and are willing to commit to on-going planning and support. The planning group's membership may evolve over time, but it would be best to have at least the following persons included for the first meeting:

- the individual who is the focus of the plan
- parent/s, and at least one other family member, especially siblings
- at least one friend of the individual or the family
- at least one representative from the community that is not a service provider
- at least one representative from an agency or human service provider
- for students, at least one representative from school who knows the individual well.

WHEN IDENTIFYING GROUP MEMBERS IT IS IMPORTANT TO REMEMBER:
Group members participate in regular meetings which may occur as often as every 6-8 weeks depending on the situation and needs of the focus person. After the first meeting, which may take about 3-4 hours, subsequent planning meetings usually last about 1-2 hours. If some family members or friends are coming from far away, they may not be able to meet with the group on a regular basis. However, they can contribute information during the initial profile and planning meetings and be kept informed of the progress of the group. There may also be others who will not continue on as part of the regular group, but have information to share in the beginning or later when special needs arise. People are welcome to join in as their time and circumstances allow, but there should be an ongoing commitment from a core group of people to meet regularly for the plan to have a good chance of success. One member of the group will take over the facilitator's role at some point. That person will be responsible for organizing and leading the meetings. The original Personal Futures Planning facilitator should be available to the group's new facilitator if needed for support.

BUILDING A PERSONAL PROFILE

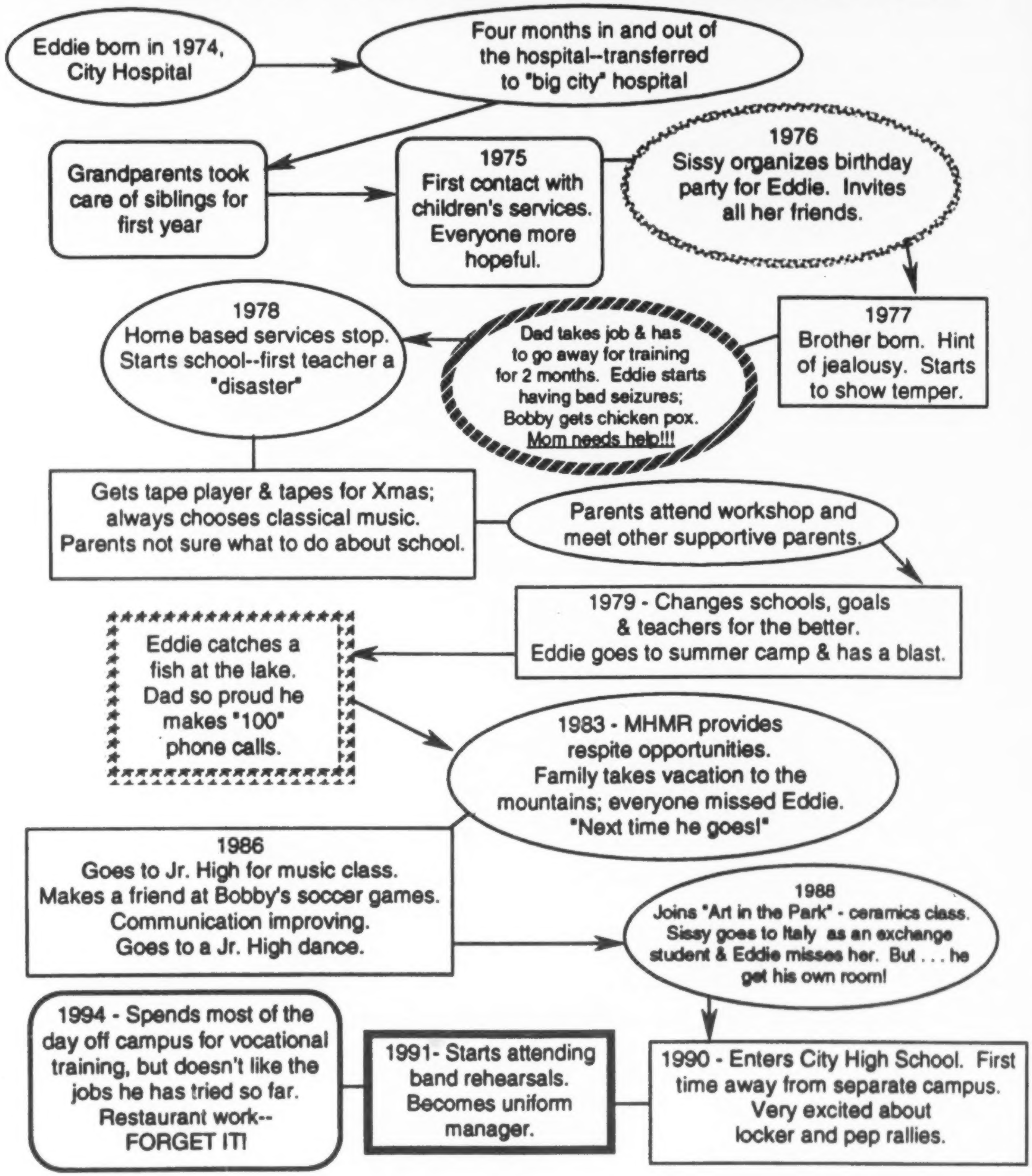
The following maps--History, People, Places, Preferences, and Images of the Future--are representative of the maps used to create a personal profile. These five maps generally apply to anyone. You might also want to map choices, communication, capacities, health concerns, contributions, responsibilities, "nightmares", or any other pertinent issue. The format for each individual's plan is unique based on his or her circumstances. The facilitator, or a scribe working with the facilitator, draws these maps on poster-size paper based upon the comments of the meeting participants. As they are completed, the maps are placed around the room so everyone can see them. As a total picture begins to emerge, participants can easily look at the many facets of an individual as they join in forming a shared appreciation of that person, and a common dream for the future.

The facilitator or scribe draws simple illustrations and uses a variety of colors while sketching out the maps. Colors can help make the maps easier for the participants to reference: green for positive experiences and opportunities; red for negative experiences and barriers; yellow for highlights, and so forth. Pictures help bring the information to life, making it more vivid for the participants. Lively maps also emphasize the more informal nature of the meeting.

When permanent records of the maps are made for the participants, the facilitator tries to accurately represent all of these pictures and the unusual design. This helps those reviewing the plan to remember the meeting better, as well as graphically reminding people that this meeting was different than traditional planning meetings that are summarized with minutes or reports.

EXPLORING THE PAST AND PRESENT

THE BACKGROUND MAP PROVIDES A HISTORY OF THE PERSONAL LIFE EXPERIENCE OF THE FOCUS PERSON AND A LOOK AT HIS OR HER FAMILY AND COMMUNITY LIFE.



Eddie born in 1974, City Hospital

Four months in and out of the hospital--transferred to "big city" hospital

Grandparents took care of siblings for first year

1975
First contact with children's services. Everyone more hopeful.

1976
Sissy organizes birthday party for Eddie. Invites all her friends.

1977
Brother born. Hint of jealousy. Starts to show temper.

Dad takes job & has to go away for training for 2 months. Eddie starts having bad seizures; Bobby gets chicken pox. Mom needs help!!!

1978
Home based services stop. Starts school--first teacher a "disaster"

Gets tape player & tapes for Xmas; always chooses classical music. Parents not sure what to do about school.

Parents attend workshop and meet other supportive parents.

1979 - Changes schools, goals & teachers for the better. Eddie goes to summer camp & has a blast.

Eddie catches a fish at the lake. Dad so proud he makes "100" phone calls.

1983 - MHMR provides respite opportunities. Family takes vacation to the mountains; everyone missed Eddie. "Next time he goes!"

1986
Goes to Jr. High for music class. Makes a friend at Bobby's soccer games. Communication improving. Goes to a Jr. High dance.

1988
Joins "Art in the Park" - ceramics class. Sissy goes to Italy as an exchange student & Eddie misses her. But . . . he get his own room!

1990 - Enters City High School. First time away from separate campus. Very excited about locker and pep rallies.

1991- Starts attending band rehearsals. Becomes uniform manager.

1994 - Spends most of the day off campus for vocational training, but doesn't like the jobs he has tried so far. Restaurant work--FORGET IT!

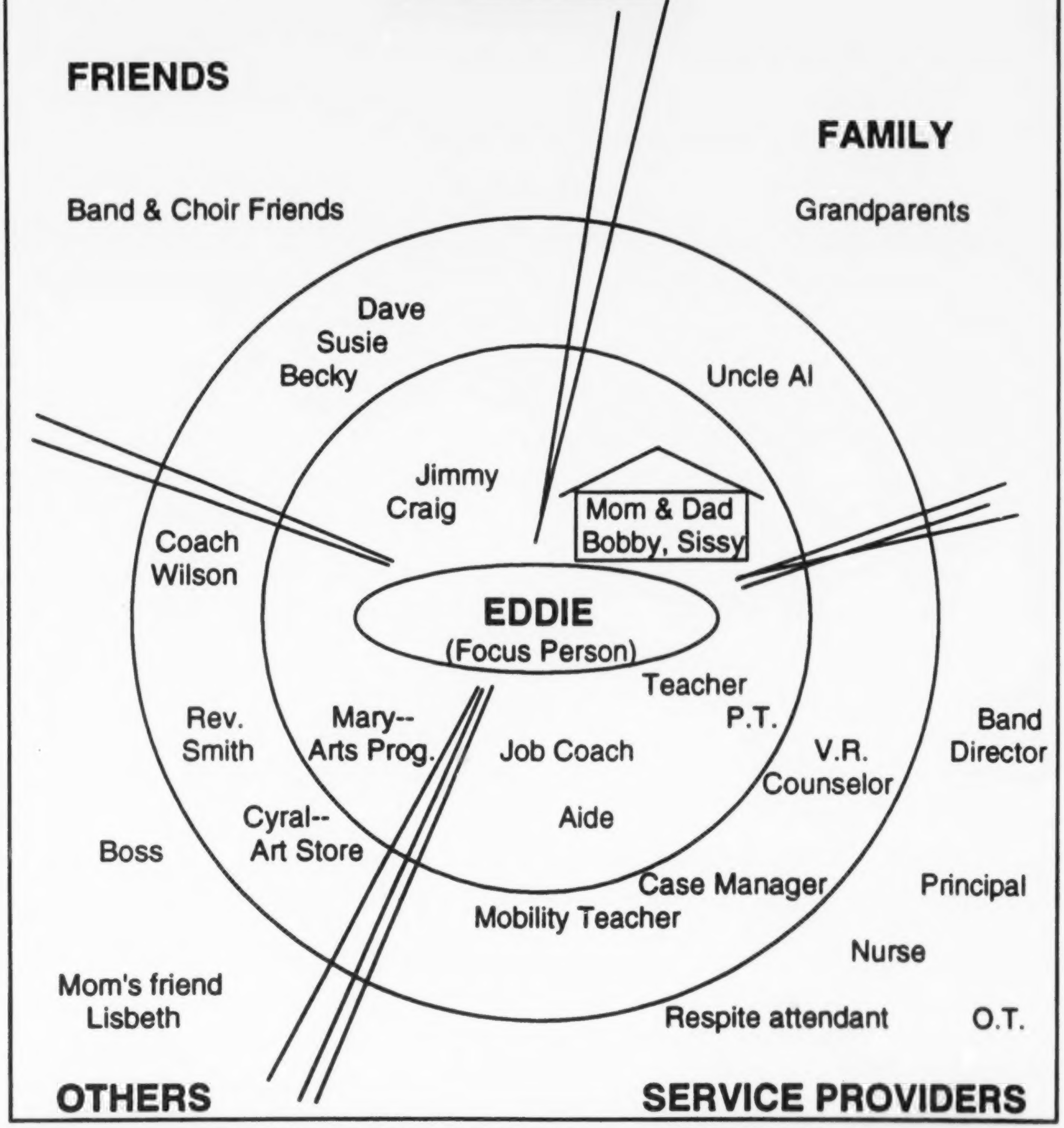
A personal history for the focus person from birth to present is generated by the group. The individual and those who have known him or her contribute information by telling stories about significant events. The background map created helps the group to understand the life experience of the focus person and his or her family.

All participants gain a greater appreciation of the individual as a whole person, with a broad range of experiences, struggles, and achievements. The positive experiences point out opportunities upon which the group can build; the problems and barriers encountered give the group a greater sense of the effort required to make good things happen. This map helps to celebrate the accomplishments and to show how opportunities in the present are often a result of experiences and actions in the past.

This simple exercise has surprisingly powerful results. Deciding what stories other people need to hear often helps participants clarify which things they feel are most important. All the participants, including the focus person and family, learn some things they never knew and begin to look at events with a new perspective.

Information collected is "mapped out" by the facilitator as the participants tell their stories. The facing page illustrates the idea of a background map. An actual map contains simple pictures of important events and has more details.

PEOPLE


FRIENDS
FAMILY
Band & Choir Friends
Grandparents
Dave
Susie
Becky
Uncle Al
Jimmy
Craig
Mom & Dad
Bobby, Sissy
Coach
Wilson
EDDIE
(Focus Person)
Teacher
P.T.
Rev.
Smith
Mary--
Arts Prog.
Job Coach
V.R.
Counselor
Band
Director
Cyral--
Art Store
Aide
Boss
Case Manager
Principal
Mobility Teacher
Nurse
Mom's friend
Lisbeth
Respite attendant
O.T.
OTHERS
SERVICE PROVIDERS

This map illustrates the person's relationships. The inner circle is for those who are closest to the person. It includes people who see the person every day, or with whom he or she has a very close bond. The second circle is for those people the individual is involved with on a regular basis. The outer area is for those people whom the individual knows and finds meaningful, but with whom there is not as much opportunity to have contact. The map indicates relationships which must be protected in future plans, and points up areas where additional relationships need to be fostered. The "Places" map on the next page is used in much the same way.

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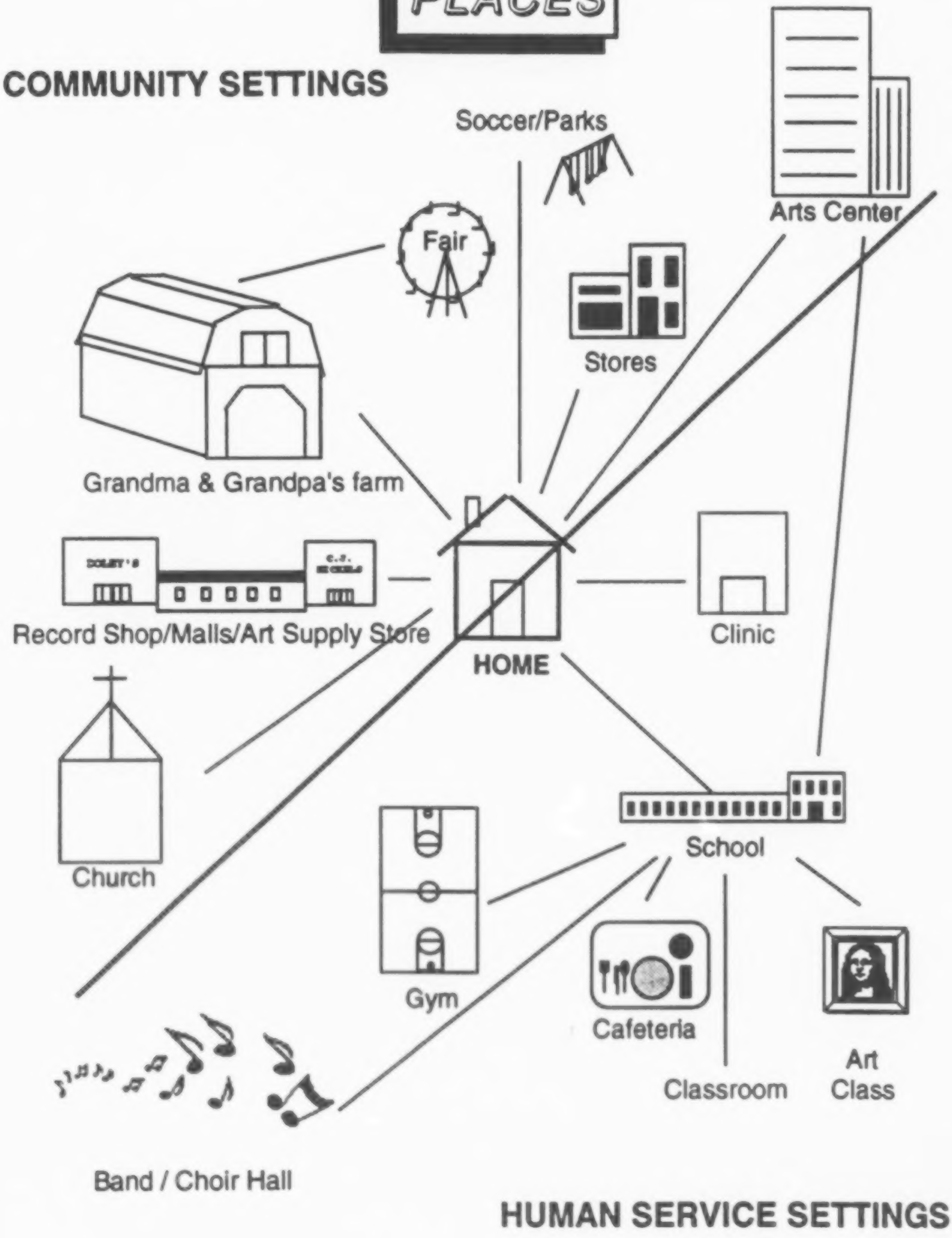
PLACES


COMMUNITY SETTINGS
Soccer/Parks
Arts Center
Fair
Stores
Grandma & Grandpa's farm
Record Shop/Malls/Art Supply Store
HOME
Clinic
Church
School
Gym
Cafeteria
Classroom
Art Class
Band / Choir Hall
HUMAN SERVICE SETTINGS

PREFERENCES

WHAT WORKS

Creates interest, engagement, joy, or is a strength

Loves music
Loves having own room
Enjoys friends from past & new friends
Getting to organize own space
Enjoys good food
Enjoys parks, camping opportunities
Likes doing own thing
Enjoys taking care of plants
Doing creative/artistic projects and going to art "happenings"
Enjoys having a pet
Enjoys dancing
Needs to have choices
Having opportunities to help others
Enjoys traveling
Enjoys working and earning money
Enjoys people and doing things with them/being in the middle of things
Enjoys kidding around, a laugh, something off-beat
Dressy clothes, looking nice

WHAT DOESN'T

Creates upset, frustration, boredom

Rushing
Being away from home too long
Too many new things at once
Meaningless activities
Being left out
Cold weather
Harsh criticism
Not getting enough sleep!!!
Not having things fully explained
Stairs/long walks
Having no control or influence
Working where it is too hot

MAPPING PREFERENCES REMINDS THE PARTICIPANTS THAT THE WISHES OF THE FOCUS PERSON SHOULD BE THE BASIS FOR THE DREAM. THE GROUP DISCOVERS CAPACITIES TO BUILD ON AND CONDITIONS TO AVOID. THIS MAP HELPS ILLUSTRATE PATTERNS IN THE GIFTS, POTENTIAL, INTEREST AND UNIQUE CONTRIBUTIONS OF THE PERSON. IT ALSO HELPS IDENTIFY PATTERNS IN THE CONDITIONS THAT BLOCK OR CHALLENGE THE DEVELOPMENT OF OPPORTUNITIES.

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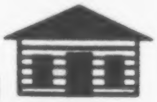
IMAGES OF THE FUTURE

New images of the future emerge as an individual and people who care explore ways to fully express the person's capacities and interests in the community. Participants bring together inner hopes and dreams with a new appreciation for the person's gifts and preferences to form a shared dream for the future. This chart helps illustrate what the focus person desires for his or her home, job, community life, and personal life. This is a picture of a dream.

HOME



- Own home in the neighborhood
- Support person to help with household chores, money management, shopping
- Someone always available for emergencies

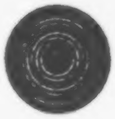
- Small yard and a pet
- One or two housemates

- Guest room for family and friends to visit
- Porch swing

- Near work or bus line
- Live near sculpture garden and art supply store

WORK

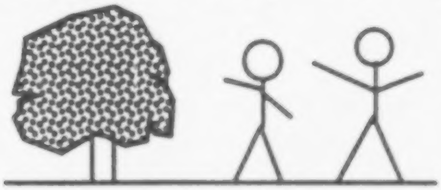
- Work around music, art, or out-of-doors
- Enjoys organizing and routine, so could work in a supportive job in an environment such as City Arts Council



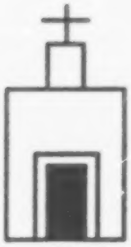
- Could work part-time and do some volunteer work, or work full-time
- Part-time work at a record or art store or volunteer work at a library or museum

- Need to make enough money to take a camping trip each year

COMMUNITY LIFE



Outside with people frequently
Lots of friends

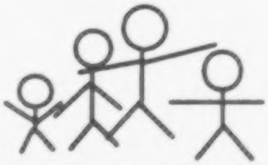


Attend church

Help pass out programs at the symphony

Would like to join a group to go camping and fishing

PERSONAL LIFE



Have time to visit family
Have friends over to visit with me and listen to music.

Go out to dinner or camping with friends

Eat dessert first sometimes

Stay up late and sleep in on Saturdays

Work on ceramics when I want to

PLANNING AND TAKING ACTION FOR THE FUTURE

After the personal profile is complete, the group works together to develop an action plan based on the image of the future. The facilitator leads the group in determining the opportunities to be explored and obstacles to be overcome in order to make the dream become reality. From this discussion the group develops strategies or action steps which group members agree to work on before the next meeting. The action plan includes steps to be taken, the person or people who will be working on each step, and a time-line. The focus of the plan may be broad or narrow, depending on what is needed at the time.

Group members may work individually or collectively to accomplish the steps, which should be specific and concrete. No assignments are made. All steps are initiated by volunteers who are willing to work on the actions they suggest. It is important that participants be realistic, and not volunteer to do too many things at once. Keeping goals simple and easy to achieve fosters a sense of accomplishment and keeps the group feeling positive and motivated.

Often the obstacles encountered by the group have to do with the limitations and constraints of service systems. Service systems can prevent a person's vision of the future from being realized if procedures and regulations are inflexible. Administrators of human service organizations need to be willing to consider systems change as a possible outcome if they lend their support to the process. New possibilities and wonderful changes may occur when systems make exceptions in order to try new ways for one person to negotiate system-centered obstacles.

The group reconvenes regularly to maintain progress and stay focused on the goals. Group members gather as often as they feel is needed to continue taking positive steps toward realizing the dream. The frequency of the meetings may vary over time based on the circumstance of the focus person and schedules of the participants. However, it is best if the group meets fairly often at the beginning, so that the momentum of the original planning meeting can be maintained, and the participants can form a sense of group identity and togetherness. It would be best if the first follow-up meeting occurs within 6-8 weeks after the initial plan is developed.

During regular follow-up meetings, group members review the progress they have made on their action steps. Goals may be modified, added, or discontinued as new obstacles and opportunities are identified. It is important that someone take notes at each meeting, so that all participants are clear about their responsibilities in accomplishing the steps of the action plan. From time to time group members should revisit the image of the future to remind themselves of the ultimate destination. The group's actions should always support this vision.

Sometimes strategies need to be reconsidered, and the dream of the future will probably change some over time. However, it is important that the dream remain true to the focus person, and not change based solely on "what's available now". The group must continue to dream, brainstorm, and develop strategies for getting around the barriers that stand in the way of the dream.

As time goes on, some group members may drop out, and new members may be invited to join the circle: people who have become important to the person or the family; people who can provide information or resources; people who want to help. This document and good notes from the follow-up meetings will help them to become a part of the group and share its enthusiasm.

ACTION PLAN FOR EDDIE'S PERSONAL FUTURES PLANNING GROUP

1. Contact the volunteer program for the City Arts Council to see if they need people to pass out programs at the symphony.	Before the next meeting.	Mary - Arts Program Director for Parks and Recreation
2. Contact Hit Records & Tapes as a possible job training site for Eddie during this coming school year.	Within two weeks	Bob - VR Counselor Anne - Job Coach
3. Invite Cyral who owns the Art Supply Store to come over for dinner with the family and share information with her about Eddie's Personal Futures Plan.	Before next Saturday.	Mom, Dad, Bobbie and Eddie
4. Contact the Arts Council to find out what art events will be happening during school hours that could be accessed during a weekly planned extracurricular time slot.	By next Monday.	Mary - Arts Program Director for Parks and Recreation
5. Find out about bus or special transit schedules for Eddie to access to get to arts activities.	By next Monday.	Dave and Susie - Friends
6. Contact the Special Education Director about providing an aide to go with Eddie to arts activities during an extracurricular time.	After Monday, but before the next meeting.	Mrs. Meyers - Teacher Mom and Dad
7. Call realtors for information about HUD, Section 8, etc. as possible sources for finding/funding a home.	Before next meeting.	Reverend Smith & Lisbeth
8. Call the Wilderness Club about membership information and schedule of activities.	Before next meeting.	Sissy

Suggested Readings on Person-Centered Planning

Beth Mount and Kay Zwernik (1988). *It's Never Too Early, It's Never Too Late.* St. Paul, MN: Governor's Council on Developmental Disabilities.

Beth Mount (1990). *Making Futures Happen: A Manual for Facilitators of Personal Futures Planning.* St. Paul, MN: Governor's Council on Developmental Disabilities.

These books by Beth Mount and Kay Zwernik are available from the Minnesota Governor's Council on Developmental Disabilities, 300 Centennial Office Bldg., 658 Cedar Street, St. Paul, Minnesota 55101, (612)296-4018.

Pat Beeman, George Ducharme, and Beth Mount (1989). *One Candle Power: Building Bridges into Community Life for People with Disabilities.* Manchester, CT: Communitas, Inc.

Beth Mount, Pat Beeman, and George Ducharme (1988). *What Are We Learning About Bridge-Building?.* Manchester, CT: Communitas, Inc.

Beth Mount, Pat Beeman, and George Ducharme (1988). *What Are We Learning About Circles of Support?.* Manchester, CT: Communitas, Inc.

Beth Mount (1991). *Dare to Dream.* Manchester, CT: Communitas, Inc.

Beth Mount (1990). *Imperfect Change.* Manchester, CT: Communitas, Inc.

Beth Mount, George Ducharme, and Pat Beeman (1991). *Person Centered Development.* Manchester, CT: Communitas, Inc.

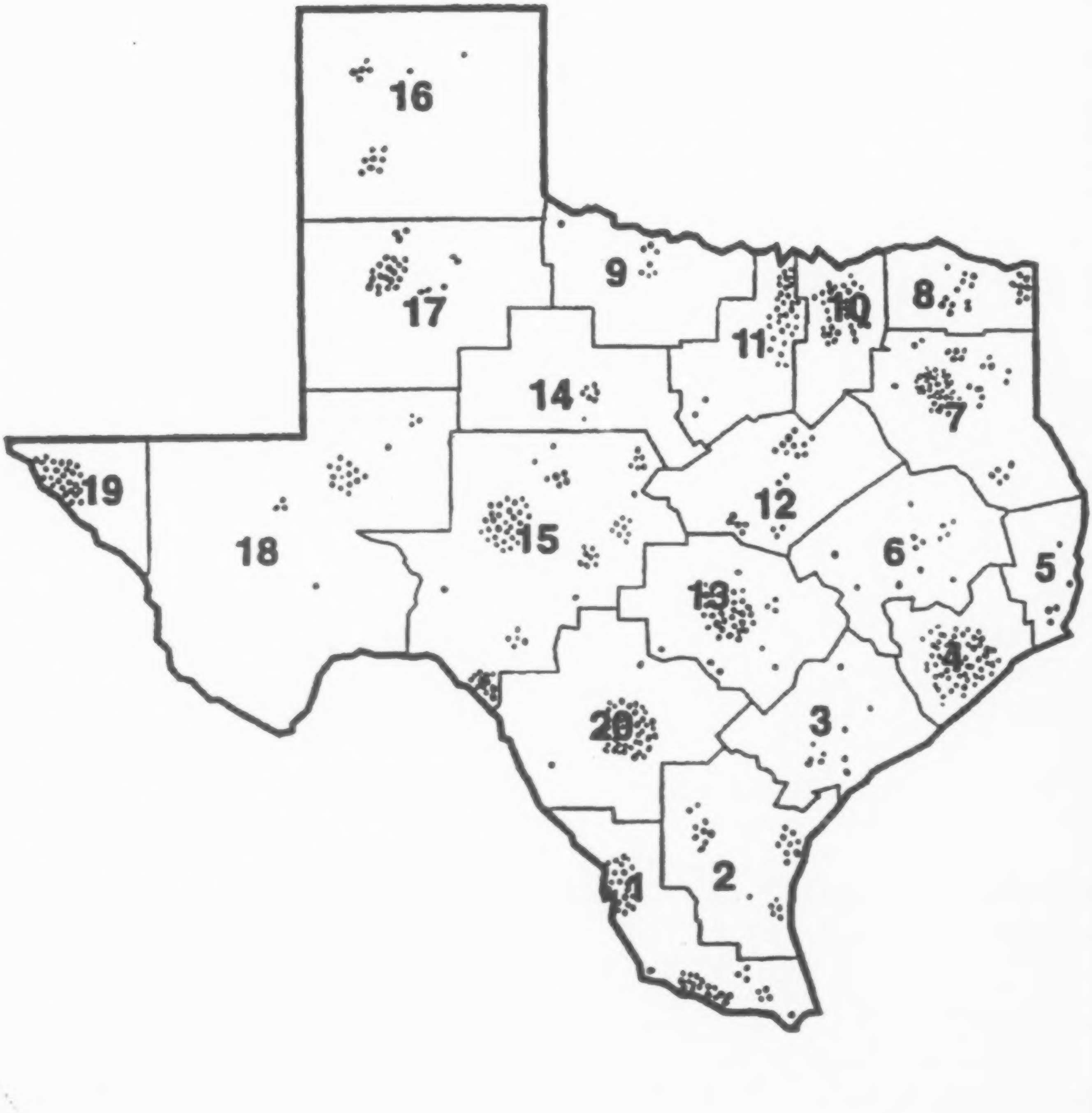
These books written by Beth Mount, Pat Beeman, and George Ducharme are available from The Community Place, 730 Main Street, Manchester, CT 06040, (203)645-3177.

John O'Brien (1987). A guide to life-style planning. In B. Wilcox and G. T. Bellamy (Eds.), *A Comprehensive Guide to The Activities Catalog* (pp. 175-189). Baltimore: Paul H. Brookes Publishing Co.

John O'Brien, and Herbert Lovett. *Finding a Way Toward Everyday Lives: The Contribution of Person Centered Planning.* Harrisburg, PA: Pennsylvania Office of Mental Retardation.

Terry Vandercook, Jennifer York, and Marsha Forest (1989). The McGill Action Planning System (MAPS): A strategy for building the vision. *The Journal of the Association for Persons with Severe Handicaps*, Volume 14, Number 3, pp. 205 - 215.

Additional copies of this paper are available from the authors at:
Outreach Program
Texas School for the Blind and Visually Impaired
1100 W. 45th Street
Austin, TX 78756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PROJECTION OF THE NUMBER OF CHILDREN WITH DEAF-BLINDNESS

A Comparison of the Number of Special Education Students With Deaf-Blindness to the Number of Special Education Students by ESC Regions in Texas

ESC Region	Number of Special Education Students 1992-1993	Federal Projection of Number of Students with D-B*	1995	1994	1993	1992
1	24,474	48-72	**38**	35	33	17
2	12,799	24-36	**25**	17	24	3
3	7,335	14-21	**8**	7	7	3
4	76,433	152-228	**75**	57	48	45
5	11,276	22-33	**4**	5	2	4
6	14,237	28-42	**13**	11	10	5
7	20,111	40-60	**44**	33	15	11
8	7,530	14-21	**19**	15	10	9
9	7,142	14-21	**8**	8	10	6
10	51,756	102-153	**31**	27	20	21
11	39,100	78-117	**50**	43	49	21
12	14,531	28-42	**30**	10	8	8
13	27,931	54-81	**40**	38	30	36
14	8,454	16-24	**12**	8	9	8
15	7,031	14-21	**73**	69	66	6
16	9,780	18-27	**16**	12	9	2
17	11,432	22-33	**30**	35	38	12
18	9,337	18-27	**15**	17	19	5
19	12,897	24-36	**25**	49	41	0
20	38,121	76-114	**38**	35	24	20
Total students per year			**594**	531	472	242

* 2 to 3 students with deaf-blindness per one thousand students receiving special education services

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P.S. NEWS!!!

Texas School for the Blind & Visually Impaired
Deaf-Blind Outreach Family Training & Support
1100 West 45th Street
Austin, Texas 78756

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(512) 454-8631

Kate Moss, Editor
Beth Sánchez, Assistant Editor

August 1995

Vol. VII, No. 3

EDITOR'S CORNER

The July edition of P.S. NEWS!!! is late because we were busy with the 1995 Symposium on Deaf-Blindness, sponsored by TSBVI Deaf-Blind Outreach which took place June 23-24, 1995 here in Austin. We waited on this edition of the newsletter so we could share some of the Symposium information with you.

The first morning of the Symposium 42 family members and 119 professionals listened to the opening remarks of the Symposium from Outreach Director, Cyral Miller (pages 3-5). Following her presentation, three case studies of children with deaf-blindness were presented.

Robbie Blaha, Education Specialist with Deaf-Blind Outreach and Ann Bielert, Intervenor with Alief ISD, introduced us to Larissa Lepik. Larissa, granddaughter of Toomas and Gretta Lepik, is eleven years old. Her deaf-blindness occurred as a result of Congenital Rubella syndrome. Robbie and Ann discussed the process used to develop and implement her program in a regular elementary school classroom. With Ann as her intervenor, Larissa has achieved many goals which include using a calendar box to organize her day, learning to be more independent in completing tasks, and using and caring for her adaptive aids (glasses, hearing aide, FM system, etc.). Her communication skills are also growing daily.

The second case study was presented by David Wiley, Deaf-Blind Outreach Transition Specialist, Delinda Henry, mother of Jamie Jackson, and Sharon English, Jamie's former TSBVI classroom teacher. Jamie, a 21 year old young man who is profoundly deaf and totally blind, has had long-term problems with challenging behavior which created barriers to learning and forming relationships. In recent years he has been diagnosed with bi-polar disorder and now receives medication which seems to help him greatly. Additionally his program was changed to focus on communication skills, relationship building, and choice making. Jamie began to make significant progress. He seems able to value the people with whom he associates. He has participated in job training experiences at a variety of community job sites where he is a valued worker. Jamie and his mother are currently preparing for his transition from the educational setting to community life as an adult.

The third case study was presented by Linda Hagood, Deaf-Blind Outreach Education Specialist and Mark O'Dell, father of Breezy O'Dell. Breezy is a six-year-old young lady who has significant vision and hearing loss as a result of KID syndrome. She has had many health issues to deal with because of this syndrome, but despite all of this, she remains an exceptionally bright, vivacious, charmer. Breezy is currently in a classroom for the hearing impaired in Amarillo ISD and receives most of her instruction in sign language. She receives individual support from an educational interpreter. Because her vision loss may be progressive, she must acquire a strong language base as quickly as possible. The challenges her educational team face include making the appropriate adaptations to teaching strategies, staffing patterns, and materials.

Later in the day families and professionals had the opportunity to visit with each other, exchange ideas and experiences, and connect with others who are involved in the lives of people with deaf-blindness. Many of the families at the Symposium had never met another family who had a child with deaf-blindness. For them, connecting with another parent or family member, was the very best part of the weekend.

On Saturday morning participants had a choice of breakout sessions. Linda Hagood presented along with Barbara Talamentez, Parent Advisor for Northeast ISD in San Antonio, and Dottie Haley, Interpreter for Travis County Services for the Deaf. "Using the Tactile Sense: Considerations in Developing Communication Skills for Students with Deaf-Blindness Who are Tactile Learners" offered a "potpourri" of information about such things as the use of tactile symbols, the use of touch cues and coactive signing, and the role of an interpreter.

Jim Durkel, Education Specialist with Deaf-Blind Outreach and an audiologist, presented "Using the Auditory System: Issues for the Child with Deaf-Blindness." This session provided basic information about how the auditory system works and underscored the importance of a good listening environment and appropriate amplification for children with deaf-blindness. Jim also discussed different types of audiological assessments and explained the benefits of each.

"Using Low Vision: Considerations in Developing Skills in Students Who are Hearing Impaired with Functional Vision" had to be cancelled at the last minute and a film festival was substituted. This was a topic that I was particularly interested in learning more about, so I decided to ask Robbie Blaha to condense that presentation into an article for P.S. NEWS!!! This article can be found on pages 11-19.

The final session of the Symposium was " the icing on the cake." We were privileged to have three wonderful speakers who brought a special expertise to the topic of "Deaf-Blind Services in the '90s". The first of these speakers was Michael Collins, Co-Chair of the National Coalition on Deaf-Blindness. Mike shared a brief history of the education of Americans with deaf-blindness and gave a disturbing glimpse into the future of services to individuals with deaf-blindness in this country (see related article on p. 3). His remarks are excerpted on p. 14 - 15.

Next we heard from Jack Earwood, Deaf-Blind Specialist with Texas Commission for the Blind. Jack shared information about resources available to individuals with deaf-blindness from the unique perspective of a professional and a person with Usher's syndrome. Jack told how important the support of his wife, his daughter, and his friends were to him. He talked about being labelled "slow" in school and how long he worked to get through college because he was not provided with any of the supports or adaptations he needed to access the information. Stressing the importance of advocacy for individuals with deaf-blindness, he strongly encouraged families and professionals to become involved in organizations such as the Texas Deaf-Blind Association (TDBA) and the Deaf-Blind Multihandicapped Association of Texas (DBMAT) and become advocates for services to people with deaf-blindness.

Our closing speaker was Kim Powers, star of "Kim's World", a children's program on KALEIDOSCOPE, the world's first disability network based in San Antonio. Though Kim is totally blind and profoundly hearing impaired she has an incredible zest for living. One of her many interests is skydiving. Kim spoke of growing up as a child with deafness and of the isolation she felt until she went to Texas School for the Deaf. There, for the first time, she was in a world where everyone could communicate with her. Kim's enthusiasm for life and her deep interest in communicating her experience to the world is inspiring.

Now, before you get further into the newsletter, I want to let you know that actions being taken by both the federal and state legislatures are likely to have a great impact on Deaf-Blind Outreach. The full extent of the impact is not clear as yet. We are currently in the final stages of negotiating the Federal CFR 307.11 grant that provides the bulk of funding for our program. The final result of this process may result in significant changes for Deaf-Blind Outreach. We hope to be able to share any of these changes with you in the October newsletter.

Action Alert from the National Coalition on Deaf-Blindness

July 21, 1995

As you probably know by now, the House Subcommittee on Appropriations reduced the Department of Education's budget by $3.85 billion dollars. The discretionary programs were hit especially hard. Funding dropped from $245 million to $78.9 million, a cut of 69%. These cuts included all funds for personnel preparation in special education.

Services to deaf-blind children were retained at $12.8 million. What is important to understand is that this does not mean that we now are safe, and have a guarantee of this funding. These figures now go to the full House Appropriations Committee on August 1, where they will either be accepted or changes will be recommended.

Congress will then break for the August recess and, when it reconvenes after Labor Day, the full House of Representatives will vote on the budget.

Indications are that the Senate will not begin its work on Appropriations until after the August recess. And then the Senate and the House will meet to discuss their differences and agree on each item to be funded. The bill will then be sent to the President for approval. So you see, we still have a long way to go.

We must let our elected officials on the full House & Senate Appropriations Committees know how devastating the cuts in all discretionary programs will be, and that we need all $245 million in discretionary programs to be continued. Please emphasize the need for personnel preparation programs in your letter.

Also: we must pay attention to the language of the IDEA act as it is re-authorized. We must make sure that our funding and our specific deaf-blind services are protected there as well. The language of the authorizing bill could hurt us as much as an actual funding cut, because it could result in deaf-blind funds being taken away for other purposes, so we must address the IDEA language as well.

In short, the most specific helpful actions are as follows:

1. The Appropriations Committee in the House is scheduled to mark up the Dept. of Education budget August 1st. Have as many people as possible contact them asking for the restoration of the money cut from the discretionary programs.
2. The House Subcommittee on Early Childhood, Youth and Families is meeting on either July 26 or August 1st to draft IDEA. Ask people to contact them requesting no change in the services to Children with Deaf-Blindness Program. Remind them that children and families desperately need these services to emanate from the Federal Government, because states frequently overlook the needs of such a low-incidence population.

Call either of us (at 617-972-7221) if you have questions about the situation and we will keep you posted, to the best of our knowledge.

Michael Collins and Joseph McNulty, Co-Chairs
National Coalition of Deaf-Blindness

Opening Remarks from the 1995 Symposium on Deaf-Blindness

Editor's Note: The presentation was made by Cyral Miller, TSBVI Outreach Director, to the families and professionals attending the Symposium on Deaf-Blindness held in Austin, Texas on June 23-24 of this year.

I have been asked to talk about what I have learned as a result of 5 years of being Outreach Director with the Deaf-Blind Outreach team. I have to confess that I came in as a pretty confident "Vision Person", and I think my basic thought was that I had the knowledge and training for what I considered a segment of the visually impaired population. Now, much humbled by my years with this team, I want to confess to you that I was wrong. But I have learned and my new knowledge is what I want to share.

1. **Deaf-blindness is not a single condition and does not describe a child**. The diversity of the students we are asked to assist is staggering. There are students who are signing and writing academic papers by hand, others who braille and use tactual signing, others who use gestures or objects to communicate, and those who are taught based on behavior states of calm, agitated, or sleeping. There are some who are totally blind and totally deaf, and others with lots of useable sensory input. When you add in the range of other factors that define a person such as age, location, interests, family setting, and learning styles, you have a wide range of people within the same deaf-blind category.

2. **Deaf-blindness has its own set of theories, methodologies, and professionals.** There is a distinct body of knowledge about this population and their needs. This has developed over the past 150 plus years. We have only heard about Helen Keller, but there is a long legacy of people who were deaf-blind, including Laura Bridgman, Julia Brace, Helen Schultz, and others who were educated in different places and times and using different methods as they have been developed and refined.

3. **Deaf-blindness is not the same as, or only a little different from, or kind of like other disabilities.** It is not approached as a sum of different areas of impairment, because the impairments become "intertwined" (Hart, 1977) into the very fabric of the person and often cannot be sorted out and addressed individually. Teachers of the visually impaired cannot simply work with teachers of the auditorily impaired and come up with the appropriate programming. It is not an additive process, but rather a different process. "The learning problems of children with dual sensory impairments differ greatly from children having a single impairment of either hearing or vision. Deaf-blind children need education and training designed to meet their special needs." (Hart, 1977)

4. **Programs must differentiate between deaf-blind students and others**. There are ways in which these children can resemble others with other arrays of disabilities and abilities. There are adaptations that may work well with a deaf-blind child taken from other fields and vice versa. Calendar systems, for example, which can provide a sense of order to a chaotic universe, can be extremely beneficial to others needing routine. But all children using calendars do not need the same kind of calendar, nor will they use the same adaptive device or aide with the same purpose or results. I think many programs nationally have gone on a loop on this issue, first specializing in deaf-blindness, then deciding that so many had multiple disabilities that the more generic severe-profound programming was appropriate, and now (I hope) seeing that despite the similarities, deaf-blind children need something different.

5. **Definitions about deaf-blindness are complex.** The federal definition indicates a student whose combined auditory and visual impairments "create such severe communication and other developmental and learning needs that they cannot be appropriately educated in special education programs solely for the hearing impaired child, or for the visually handicapped child, or the severely handicapped child, without supplementary assistance to address their educational needs due to these dual, concurrent disabilities. If you don't know what to look for, in some children it can appear that they are not deaf-blind. It takes specific kinds of knowledge to correctly evaluate a deaf-blind child's state of being.

6. **Deaf-blind children are most often not served by people who know very much about their needs.** Formal graduate level training for teachers in this field only began in 1956 at Boston University. Prior to that there was total reliance on untrained teachers and/or caring individuals who devoted themselves to learning on the job, or through short term summer courses. There were more training programs begun in the 1960's as a response to the Rubella epidemic, but there are still few programs training teachers specifically for this population, and few states where such certification is even required or recognized. If you call for assistance at the regional education service center in your area, you will

find that there are no specialists there hired to focus on persons with deaf-blindness. There are no local teachers with specific training who apply that to caseloads exclusively of deaf-blind students. There have been chronic and serious shortages of trained teachers for these students forever.

7. Most teachers and programs serving deaf-blind students were and still are learning through inservice training. Despite the general deaf-blind body of knowledge to be applied to each child in a unique way depending on his/her own needs, most teachers rely upon 1 and 2 day workshops for the majority of their formal learning. Very few other professions must rely upon such a hit and miss method of disseminating practical information. It puts an enormous burden on each of you who are working, living with and learning about deaf-blindness to communicate, to network, and to share your information with each other, because that is the inadequate but actual way that communication in this field is done.

8. Deaf-blindness is a VERY low incidence population. In Texas, there are hardly any districts where more than one or two students with deaf-blindness reside. It is hard to get knowledgeable staff trained in the field when all they really get to know is one student. In many cases, that one student is on their roles a short time and then gone and there may not be another for several years.

9. There are not many resources close to the deaf-blind children themselves. Prior to 1963 there were 7 residential programs in the country, serving 125 deaf-blind children, and another 150 enrolled in public or private programs. With the Rubella babies swelling the numbers, Title VI-C of the Elementary and Secondary Education Act resulted in model centers across the nation. The early regional centers, set up in 1968, developed services for evaluation, adjustment, orientation and education, and consultation to parents, teachers and concerned others.. The emphasis shifted to technical assistance projects like the Deaf-Blind Outreach team here in Texas. Now there is reason for concern if even this level of specialist assistance will continue to be funded at the federal or state levels.

10. A key to understanding deaf-blindness is understanding that communication is all. As a result, ACCESS to learning, to information, to interactions with others, is the prime issue. I have learned that with training, it is possible to determine how to help a deaf-blind child or adult develop systems of communication that give the increased access to all the richness of the world. I have come to believe in the importance of granting these special children the time and energy, the devotion and caring, to find that path into the world.

I hope this symposium will help you to learn some of those specifics, some of that particular knowledge that you can take back and apply with your children and students. We need to communicate with each other while you are here and after you leave. I look forward to spending the next two days learning and talking with everyone here.

Reference:

Lowell, E.L. & Rouin, C. C. Eds. (1977). Training of personnel. *State of the Art: Perspectives on Serving Deaf-Blind Children.* Sacramento, CA: California State Department of Education, pages 238-245.

Education Issues: Deaf-Blindness in the '90s

excerpts from a presentation made at the 1995 Symposium on Deaf-Blindness
by Michael Collins, Co-Chair of the National Coalition on Deaf-Blindness

LOOKING BACKWARD AT RECENT HISTORY

The past two decades have seen some interesting changes in our service delivery to deaf-blind people. In the '70s we witnessed the creation and development of a network of multi-state regional centers for deaf-blind children. While they varied in number and composition over time, these centers provided a national network of communication and sharing for those serving children. They tended to be staffed by personnel who had specific training in deaf-blindness, and their staff provided ongoing training and consultation to local programs, and produced many publications and training videos which were nationally available.

Most importantly, the Regional Centers had the responsibility to develop direct service programs for deaf-blind children, prior to the enactment of mandatory education legislation. As a result, from about 1970 to 1975, most states had developed several specialized programs for the deaf-blind, within residential schools, state institutions for the retarded (as they were then known), and many public schools. Many "deaf-blind programs" resulted. Some of our bigger states, like California and Texas, had classrooms for deaf-blind children scattered all over the state, within some of their major school systems.

However, these programs were virtually all either in segregated settings or were mostly segregated classes within a public school setting. Another shortcoming is that not all children within the state were served by these specialized programs. Prior to P.L. 94-142, these programs could be selective about admissions. Children not admitted into these classes were either served in other generic programs for children with varied handicaps, or were not in an educational program at all. The personnel within Regional Centers had a responsibility to support, develop and advise the specialized deaf-blind programs within their region; but they also had a very large consultative caseload of children who were in no specialized service.

Another significant characteristic of this decade was the establishment of several university programs to prepare personnel. Programs to train teachers were initiated mostly with federal support (Campbell, 1976). We were educating over 100 teachers annually who had specific training. Through the Regional Centers, the graduates of these programs were readily placed in positions teaching deaf-blind children throughout the nation.

During this era, not only was the supply of teachers better than now, but these teachers, actually had jobs to go to which were related to their training. A trained teacher could get a job teaching children who are deaf-blind in any state in the nation. In addition, with some experience, they were able to fill the many specialist positions within Regional Centers, State Departments of Education, and Universities. We had a pool of people from which to recruit our future leaders. Consequently, many of our states had personnel in leadership positions who had both training and direct teaching experience with the population. (Campbell, 1976)

What was instruction like during these years? Well, many children were taught in self-contained classes of deaf-blind children, with 4-6 children being taught by a teacher and several aides. Instruction therefore tended to be carried out in classes with very low staff:student ratios. Frequently the teacher had specific training in either teaching children who are deaf-blind or children with multiple sensory impairments. When such training was lacking, the teacher knew nonetheless that he/she had accepted assignment to a class of children with deaf-blindness, and therefore the teacher participated in all possible training activities, read about the instructional techniques used with the population, and gradually acquired useful teaching skills.

Instructions tended in many programs to be very developmental, with a focus upon academic or "pre-academic" teaching. The teaching of language skills, cognitive skills, reading, writing, math, and sensory development prevailed, and in many schools the teaching of these was very good. Teachers knew how to check the child's hearing aid, knew several possible language modes and how to teach them, could teach braille when needed, could carry out auditory training, utilized appropriate assessment tools, implemented curricula to stimulate the use of residual vision, and had the ability to teach children to use these skills in everyday life situations. The teaching of daily living skills was usually well-integrated into the curriculum.

In some places the academic content was overemphasized, to the neglect of functional curricula; while some basic daily living skills were taught, too often other practical, applied skills were lacking. Frequently the activities were not terribly age-appropriate, with adolescents required to engage in very juvenile activities. Elements of choice-making and self-determination were frequently lacking from the curricula. Vocational training was either non-existent in some schools, or in others was oriented toward preparation for sheltered work. In short, much of what became state-of-the-art instruction in the '80s (Snell, 1987) was typically not addressed.

THE CURRENT STATUS OF EDUCATIONAL SERVICES

Our entire philosophy of education of children with disabilities has shifted in several ways since the 1970s. We have moved from conducting education solely in segregated facilities to offering more services integrated into the local community. We have moved from centralizing our service offerings to decentralizing them, so as to make them available in every child's community. Functional curriculum which is age-appropriate has replaced a lot of academic teaching. Vocational training and placement is now regarded as a key aspect of school curriculum. We have shifted from offering services which were highly specialized to the child's specific disabilities, to offering a curriculum which is more "generic", being generalized to all children.

These general trends in special education have had some tremendous impact on how children who are deaf-blind are educated. The typical scenario today is that the child is taught in his home community; his classmates are other children with multiple impairments, or with no impairments; his teacher has no specific training in deaf-blindness; a trained person may consult with the classroom monthly or annually; his classes focus on many functional skills, but are weak in academic teaching, sensory development and language skills; as he approaches adolescence, he probably has a reasonable program of vocational training, depending upon the community in which he resides; and his parents may not know what to do with him at home, or may be in need of a knowledgeable person to advise them.

We have a fairly strong level of technical assistance being provided through our nation program for deaf-blind children. Within each state, the single and multi-state centers for deaf-blind children have primarily a technical assistance role. The technical assistance project called TRACES has been a fine support to all states as they attempt to upgrade their deaf-blind services. Helen Keller National Center's Technical Assistance Center fulfills a similar function for transition-aged students. Both of these projects sponsor training nationally, and publish newsletters with good information for the field. Similarly, the American Foundation for the Blind's project to provide training tapes and learning modules in communication and mobility will be a wonderful resource for all of us who have the job of providing basic training on an ongoing basis. We also now have a national information center and clearinghouse being developed so that the important literature and resources on deaf-blindness will be catalogued and easily accessible to all.

Thanks to the enactment of P.L. 94-142, we live now in an era when all children receive educational services. No longer will we have to see deaf-blind children sitting at home uneducated, due to distance, funding shortages, or rejection.

The integration movement has definitely resulted in a much greater dispersion of deaf-blind children. While they used to be served in more concentrated pockets, due to the greater abundance of specialized programs, they are now served in a much greater number of schools, spread over a much larger geographic area.

The population dispersion makes the State Coordinator or Consultant's job a much more challenging one. How does a (he) adequately assist and support programs for 185 children who are in 138 different schools in the state? These 138 schools definitely require a greater level of such assistance than in the past, since they do not typically employ specialists in deaf-blindness. With only one or two children per building, or often per district, they cannot possible afford such a low incidence specialist.

(These) factors result in most states repeating training, again and again, in the very elementary instructional strategies known to be effective with deaf-blind children, for an ever-changing body of learners. The result is that very few educators are accumulating the larger body of knowledge which they need in order to conduct sound educational planning for children.

If we had personnel shortages in the past two decades, they are now increased ten-fold. Only three or four universities nationally now receive federal support for pre-service programs to train teachers of children who are deaf-blind, and are training no more than 20 or so teachers annually. Many other Universities offer programs in severe handicaps, but there is great variation in the extent to which they address sensory deficits, and too frequently deaf-blindness receives only cursory attention. Please recall that this is occurring in an era when the need for such trained teachers is at an all-time high, since children are served in such a great number of places. Local school systems, who have the mandate to educate the child, must proceed without personnel with the expertise to train and support their teaching staff.

The current era is also one in which funding is less than adequate and definitely harder to access. The federal section 622 program currently allocates $12.8 million for services nationally. This obviously buys far less service at today's costs than could be purchased for $16 million in the early 1970s.

A good summary of our present shortcomings is found in the words of Dr. Davila, "This philosophy, which has at its heart the full participation of individuals with disabilities in every aspect of community life, has in some ways, outstripped our present ability to make the philosophy a reality for all whom it embraces....Although we in OSERS embrace the concept of full inclusion, we also believe that our philosophy outstrips our present capacity to achieve it fully."

Likewise, OSERS cautions schools that the least restrictive environment for a deaf child may not be the regular classroom. Because of the "inherently isolating" nature of deafness, and the special problems children who are deaf have in acquiring language skills, "effective methods of instruction that can be implemented in a variety of educational settings are still not available", OSERS says. The notice goes on to say that "this lack of knowledge and skills in our educational system contributes to the already substantial barriers to deaf students in receiving appropriate educational services...Any setting, including a regular classroom, that prevents a child who is deaf from receiving an appropriate education that meets his or her needs, including communication needs, is not the LRE for that individual child" (Federal Register, 1992). If true for deaf children, do not these principals apply even more to the child who has both a hearing and a vision loss?

Deaf-blind children typically require certain educational content within their IEP, if their education is to be appropriate. Like all severely handicapped children, (they) need functional curricula, age-appropriate activities, vocational training, social interaction with peers. However, an educational plan for a deaf-blind child must minimally incorporate some other things including:

* Language goals in the child's most useful modalities, and written at the child's current language level.

* Sensory development activities. These would typically include auditory training following an established developmental sequence, and, in the case of partially-sighted children, low vision stimulation activities which also follow a developmental sequence.

* Teaching strategies which incorporate the child's most likely learning styles, as determined via appropriate assessment strategies. It is critical to know with what kind of instructional ratio does the child learn best; how the child copes with distracting environments; where materials are best placed for the child to attend to them; the size, shape, and color of materials which the child can see; how structured the environment and teaching day must be, for the child to make sense of his world; ecologically, what things in the child's environment promote vs. impede learning; ...and so forth.

* As appropriate, mobility training to assure the person's ability to explore and interact with their environment, to the maximum extent possible for that individual.

* Emphasis upon expanding the student's cognitive skills and to (adapting) the curriculum to accommodate for the fact that they cannot observe this world very well. Such adaptations may include (but certainly are not limited to) more tactile exploration opportunities, more use of models and real objects to explain concepts, more reliance upon field trips and actual experiences as opposed to class discussion, more preparation of descriptive information to accommodate for the student being unable to see instructional materials, and more individual interpreting of the events occurring in the classroom and the environment at large. The young deaf-blind child needs specific instruction in the use of objects and their various functions, gradually expanding the child's use of objects through incremental instruction. These concepts need to be specifically taught, again because the deaf-blind child often cannot observe how others in the environment make use of objects (Enright, 1977).

* Assessing the child's present capabilities for social interaction, and creating situations which assure the opportunity for such interactions to occur. Often the deaf-blind child needs to be specifically taught social behavior, from the earliest acceptances of others into his life space, to relating to others through language, playing of games with others, and turn taking. Again, if the deaf-blind child does not witness the social interactions of others, he has no model for this kind of behavior to occur spontaneously, and therefore often needs specific teaching to acquire such skills. Obviously, for students with a developed language system, it is important for social interactions to be in the child's primary language mode if they are to be "quality" interactions from which the deaf-blind student might benefit, and if progress in social development is to be achieved.

* Regardless of functioning level, any student who can benefit significantly from currently available educational technology must have access to it, and must have appropriate instruction in its use. This is true whether we are talking about a head-switch for a child with severe cerebral palsy, or print-to-braille computer software for the mainstreamed student.

In addition to the above factors, for students who have the academic capability, there are some other curriculum considerations if an educational program is to be judged appropriate. First students must have the opportunity to learn to read and write. Students with the ability to learn it have a right to be literate, and we have the obligation to teach them. Whether this capability can be achieved through print, or whether the child can only learn to read through braille, if they can be literate, they must be. Likewise, if the student is able to follow a reasonably "normal" sequence of courses, and earn a high school diploma, they must be afforded this opportunity. To "track" students who have the ability to earn a diploma into a "special certificate" track, only because we don't know how to adapt the curriculum for them, is doing them an injustice.

I would submit that, all too often, the above specific content needed by the child, by way of his deaf-blindness, is altogether lacking. This is frequently true both in full inclusion programs as well as in some of the segregated classes for severely handicapped children, in which deaf-blind children happen to be served. Sometimes a teacher of the hearing impaired or visually impaired, or a resource person in moderate or severe special needs, will consult to the classroom on a regular basis. However, far too often, this is not a person with real expertise at assessing the child's needs and offering a curriculum which incorporates the above factors. The result is that the child receives a program which is only partially appropriate. Some needs get addressed in the IEP, and others are overlooked, based on the expertise of the people at hand.

Sometimes, not only does the district lack this expertise, but there is also nobody to call upon from the county, the intermediate school system or the state. Therefore, the consultative input which is provided is also addressing only a part of the child's needs. A comparable lack of expertise on the part of the resource people in the state will produce the same gaps in the appropriateness of the student's plan.

This situation is not acceptable. We cannot continue pretending that a system with such large gaps is a functional system. We will never improve the quality of what deaf-blind children receive at the local level unless we all acknowledge that significant improvements are needed. This acknowledgement must be made at every level, from the U.S. Department of Education down to the newly hired teacher aide who has been assigned to a deaf-blind child for the first time. To fix the problem, we must first admit the problem.

A BRIGHTER FUTURE
ACTION STEPS FOR OSERS

Many of the problems which we are experiencing in deaf-blind education today have evolved due to a rapid shift into a decentralization of consumers. The perspectives on the needs of the population must be shaped by those who work directly with people, and not only those employed in universities or "grant factories". It is beyond my understanding why a national program to benefit a specific population does not have an advisory committee made up of consumers and professionals in the field.

ACTION STEPS FOR OURSELVES

In addition to altering the practical means by which services are delivered and personnel are trained, we must also amend our philosophical orientations. There are several issues which I believe we must confront within ourselves if the future is to be an improvement upon the present, rather than just a repetition of it.

1. First, I would remind you that current educational philosophy within our field is away from specialized services and toward more generic services. **We** must stand firm in our refusal to accept generic vanilla for a population whose needs call for Howard Johnson's 28 flavors. An endorsement of generic services is an endorsement of the current inadequacies in our system, and silence is always an endorsement.

2. We in special education have a "bandwagon" mentality to our prevailing philosophies. Just consider the buzzwords of the past couple of decades: task analysis, behavior modification, patterning, sensory integration therapy, coactive movement, vestibular stimulation, least restrictive environment, age-appropriate, ecological, mainstreamed, non-aversive treatment, integration, facilitated communication, and full inclusion. Our tendency is to jump on the bandwagon of the latest buzzwords, and act as though everything we know previously is obsolete and irrelevant. A scientific body of knowledge does not accumulate in this manner, and neither does a sound educational philosophy.

3. We must draw upon the strength of our convictions, to advocate for what is right for deaf-blind children and adults. In the past, when prevailing educational philosophies or administrative priorities were resulting in harmful results for our populations, we have been less than outspoken about these effects. We must not hesitate to point out inadequacies in services when we see them. We must help when we know what is needed, and admit it when we do not know. We must insist upon the level of specialization which this population requires, because nobody else will. We must serve as advocates for the population, and be willing to go to hearing or to court to defend what deaf-blind people need.

4. We must start to focus more upon the quality of the instructional and programmatic content which deaf-blind people are receiving, and to focus less upon the place in which the person is served. The quality of services is determined by many indicators, of which the number of non-disabled peers in the environment is only one.

5. Permit me to deviate for a moment to quote F. Scott Fitzgerald: *"The mark of a truly first-rate intelligence is the ability to hold two opposed ideas in mind at the same time and still maintain the ability to function."* WE must begin to integrate our values upon the benefits of integration and the benefits of knowledgeable expertise. We have acted as though these two ideas are diametrically opposed, when in fact specialization should be able to happen quite nicely in all settings. We have argued excessively about **where** children should be served, and not focused enough upon **what** they should be receiving.

To paraphrase Lori Goetz, "You know, all this emphasis on integration and inclusion has been very good, and it's very important....and we should keep doing it...however, these children need more than good friendships and social interactions with non-disabled peers...we forgot that they have to learn something...we somehow have to refocus to assure that each child learns as well, and has appropriate educational content." She went on to say that several of the inclusion programs with whom she works are having considerable difficulty offering appropriate instructional content. She summarized in these few words what the entire point of my presentation is about today.

These times of change in service delivery have been turbulent times, which have made us all at least a bit insecure about our values and priorities for services to the deaf-blind populations. To borrow the words of Dr. Davila again, "...I foresee a time when will look back to the 1990's, to our frustrations, our growth, our change, our successes and failures, and we will see them as steps in a long, often painful, but ultimately worthwhile process" (Davila, 1990). I would hope that we will also look back on these days of change and be proud that we insisted upon a standard of quality education for deaf-blind children throughout our own changes and evolutions.

Issues Regarding the Assessment of Vision Loss in Regard to Sign Language and Fingerspelling for the Student with Deaf-Blindness

by Robbie Blaha, Education Specialist, TSBVI Deaf-Blind Outreach

NEEDS OF CHILDREN WITH DEAF-BLINDNESS

When a child is deaf or hard of hearing, his access to information and interaction relies heavily on the visual channel. Since sign language and fingerspelling are intensely visual in nature, vision loss affects the child's ability to access and acquire these communication forms. For this reason, it is important to address any vision loss which might impact the student's ability to access educational information.

The effect of the student's vision loss on the acquisition and use of visual communication forms needs to be evaluated so that appropriate adaptations can be implemented. The communication assessment, Functional Vision Assessment, or Learning Media Assessment (LMA) do not routinely address this issue. Because this issue is so complex, assessment of vision must be carefully planned for and carried out.

Working with educators in Texas, we have developed an approach to evaluating the impact of vision loss on the child's ability to access and learn information through these communication forms. I wanted to share this information, hoping it might be useful to others facing the same task.

PREPARING FOR THE ASSESSMENT

Assemble the assessment team

Obtaining the information that is needed requires a team approach. The evaluation process requires someone who can understand what the child is signing, what is being signed to the child, and what specific visual obstacles must be over come for the child to learn and use these forms of communication. Specifically, the team needs to include both a teacher of the visually impaired and a teacher of the deaf or hard of hearing. Both these teachers have critical information that the other lacks, requiring collaboration between them.

The team may also need support from a professional with a background in deaf-blindness. Specific training on the assessment and development of programming for students with deaf-blindness is not covered in training programs for teachers of the visually impaired or for teachers of the deaf or hard of hearing. This information is peculiar to the field of deaf-blindness. In addition, the classroom interpreter is trained to provide services to individuals who are deaf or hard of hearing, but may also be unfamiliar with the adaptations needed for the deaf-blind child to access these forms of communication.

Conduct standard screenings/assessment

The process of evaluating the effects of vision loss on recognizing and using visual forms of communication is tied to the Functional Vision Assessment and the Learning Media Assessment (LMA). Conducting these assessments is the primary responsibility of the teacher of the visually impaired in collaboration with the team. As a team you should determine how to gather this information. The teacher of the visually impaired can report the impact of the student's vision loss on signing and fingerspelling in either the Functional Vision Assessment or LMA.

Compile information

After the Functional Vision Assessment is completed, the team needs to compile some specific information.

1) What is the child's etiology?

There are a number of syndromes which have both a vision and hearing loss. This may have bearing on the best educational approaches to use with the child or give direction to long-term medical follow-up. For example, Usher Syndrome brings about a visual field loss. Children with Congenital Rubella syndrome have a risk of developing cataracts and glaucoma. Resources such as the National Organization for Rare Diseases (NORD) and D-B Link can be very helpful in obtaining this important information. There are other etiologies besides syndromes that can cause vision loss. An example of such a condition is spinal meningitis. Cortical visual impairment (CVI) can be associated with this condition and results in fluctuating vision and possible perceptual problems.

2) What communication system or methodology is being used with the child?

There are several manual communication methodologies or systems being used in Texas classrooms at this time. A sentence or thought can be expressed in different ways, depending on which communication methodology or system is used, resulting in different visual demands on the child. **Chart 1** gives some very simple definitions of these methodologies or systems. (Chart 1 is not comprehensive and only meant to introduce you to these terms. It is not meant to be an endorsement or criticism of any of these methodologies or systems.)

CHART 1 - Manual Communication Systems and Methodologies

American Sign Language: (ASL): "the native language of thousands of Deaf people who have Deaf parents. For them, it is not only a first language but also carries with it the culture of generations of Deaf people in America. Like other foreign languages, it has its own history, idiomatic expressions, structure and grammatical rules." It is a highly sophisticated visual language and it is not based on nor is it derived from English. (Humphries, et al 1980.)

Signing Exact English (S.E.E. signs): A sign system developed in the early 1970's which is based on the English Language. "The most important principle in Signing Exact English is that English should be signed in a manner that is as consistent as possible with how it is spoken or written...." (Gustason, et al 1993.)

Fingerspelling: Individual letters of the alphabet are produced manually by the dominant hand through specific handshapes. In this country, we typically use the American One Hand Manual Alphabet. It can be used in conjunction with sign language.

Total Communication (TC): English is spoken and signed simultaneously using English syntax and grammar.

Observe the child

There are tests designed to check for receptive sign vocabulary. However, these tests typically give the student the advantage of seeing one sign at a time, from a consistent distance, and with a limited number of responses. The results may accurately indicate the signs that the child knows in a clinical environment, but tell you nothing about his ability to recognize them in other environments or situations. His vision loss may impede his "functional" comprehension of these communicative forms.

Therefore, you must observe the child in these real environments and situations. Typically, we have taken the questions which follow and let these guide our observations of the child in a variety of interactions throughout his regular day. These observations are carried out over the course of several days so that we can get a broad sample of the child's functioning.

A note of caution about what you observe: It is possible to overestimate a child's receptive communication skills. For example, the student may be able to tell that someone is signing without actually discriminating discrete segments of the sign or signs. For example, the teacher holds up a yellow art folder and signs "Time for art". Twenty feet away, he can see the art folder, note the teacher was signing, and guess that she was telling him to go to art. That does not mean this child can discriminate all signs at twenty feet.

Since this guessing method works best in familiar routines, you might expect to observe a significant drop in the child's comprehension of sign language in new situations and environments. He may require different instructional distances to read signs without contextual cues or when presented with novel information.

ASSESSMENT QUESTIONS AND POSSIBLE ADAPTATIONS

What follows is the list of questions that guide the observations along with some considerations and possible modifications, adaptations, or teaching strategies that may be considered. This list is by no means comprehensive. There may be other questions your team wants to address. The adaptations you select are highly individualized and should be based on the individual child's vision and signing preferences.

1) What is the best signing/fingerspelling space, placement, and distance for the child related to his visual fields?

As a rule of thumb, manual communication takes place within a two foot cubic area. Students with field losses (blank spots) in their vision can have considerable difficulty in seeing signs depending on the location and size of their field loss. Missing parts of the message can greatly affect comprehension. It is important to know the child's best area for viewing manual communication. In order to make this determination, you will need to know the best placement (e.g., central, upper, left, or right quadrant) and signing space (e.g., a radius of 10 inches) for that child. If the student has a field loss, moving further away from the signer, allows him to see more of their body and provides him more of the signed information. When a child has both an acuity problem (blurred vision) and a field loss, finding the best distance becomes a much more complex issue.

In your observations, take note of a student who keeps backing up, when you try to sign to him. He may be trying to see more of you in his reduced fields. Also watch for students who touch your wrist or hand, reach out to reposition your hand, pull their head back or use eccentric viewing positions (e.g., always turns head down and to the left to use their peripheral vision). Teachers may report having trouble getting the child's attention from a particular side. Try systematically signing from different distances and locations within a quadrant. Compare these observations with the information obtained from the Functional Vision Assessment. Do they confirm where the best viewing area is for the child?

Adaptations you would consider:

* Reduce signing space. (e.g., The sign "country" could be signed between the wrist and the elbow rather than at the elbow.) This may be helpful to students with field losses because it moves the sign into their visual field.
* Fingerspell (rather than sign) some words if the movement of the sign takes it out of the child's field of vision (e.g., "Russia" which is signed by placing the hands on the hips).
* Substitute a sign which requires a smaller signing space as long as the meaning is not changed.
* Alter the signing distance (based on the type of field loss) between you and the deaf-blind person.
* If a teacher or an interpreter has several other signing students, an additional staff person may be the best modification for the student with deaf-blindness. Presenting signs consistently in the same field, at the same distance, and within a precise area, or continuously using modified signs can be difficult if not impossible in a signing classroom.
* Consider the use of low vision aids to increase the amount of information the child is receiving (e.g., expanded field telescopes).
* Allow the child to turn his head to use eccentric viewing positions if needed.
* Use tactual signing or (tactual) tracking in some situations.

2) What is the best distance and rate related to acuity for signing and fingerspelling to enable the child to efficiently read in different instructional or conversational situations?
The appropriate distance and rate for signing and fingerspelling can vary according to the complexity of the exchange, the amount of contextual support to aid in guess work, and the characteristics of the individual sign or letter. Some signs are very concrete and have big, clear movements (e.g., "brush teeth"). Some signs are more abstract and have subtle, less discernible movements (e.g., "seven"). Signs may also resemble each other (e.g., "purple" and "green"). When fingerspelling, the hand stays in one place eliminating the types of cues many signed words provide. For example, "king" is distinctive because of the movement from shoulder to hip. Also, some fingerspelled letters are remarkably similar for people with acuity losses (e.g., a, t, n, m, o, s, e). The typical rate for fingerspelling is a rapid 3-4 letters per second and this may present a problem for the child who is visually impaired.

Distance from the signing partner also must be considered. If the student has acuity problems, he will have to be close enough to his partner to bring the person's hands, face, and torso into focus. The appropriate distance and rate of signing or fingerspelling is based on the child's rate of comprehension and can vary across settings.

When you put any number of signs (and/or fingerspelled words) together, you may need to sign more slowly and distinctly. This is very difficult to do when you have other students to consider. However, you must find the approximate rate that is most visually accessible to the child with vision impairments.

Adaptations you might consider:
* Vary the rate of signing and fingerspelling according to the situation such as when the information is complex or novel.
* Work individually with the child to improve his comprehension of signs and fingerspelling through receptive drills.
* Make specific determinations about the best receptive distance for him in a variety of situations.
* Use tactual signing and/or fingerspelling when necessary (see tactual signing question).
* Consider the use of low vision aids to increase the amount of information the child is receiving (e.g., a monocular distance aid).
* Consider the use of additional staff if the distance and rate differs significantly from that required by the other students in the class.

3) Can the student visually discern movements which give meaning to the signs?
In ASL you use an intricate combination of manual sign and nonmanual signals. These must be viewed simultaneously because the nonmanual signal alters the meaning of the sign. A few examples of nonmanual signals are: pursed lips, puffed cheeks, a raised eyebrow. When specific signals combine with the manual sign for a word, the meaning changes. (Baker & Cokely, 1980) The child can perhaps see the large hand movements, but not be able to see the more subtle movement of the eyebrow. Therefore, he misinterprets what is said.

Look at the child's overall comprehension of information that is being presented. Also consider the child's ability to read peoples' moods or intents communicated through body language. Try some imitative games which require the child to be able to attend to facial movements and hand or body movements at the same time. Do they see both movements at a variety of distances?

Adaptations you might consider:
* Providing this information in some other form. For example, instead of relying on your facial expression use additional manual signs to convey the emotion (e.g., sign "suspicious" as well as narrowing your eyes).
* Teaching that feelings are expressed through body language. The child with a vision impairment may be unaware of that.

4) *Does lighting affect a student's ability to visually access information?*
For some children, dim or very bright lighting may present challenges. As one friend who has visual impairments put it, "Light can either be my best friend or worst enemy."

Observe the child's ability to understand and respond to manual communication in different lighting conditions. Watch for changes in skills as he moves indoors and outdoors, under fluorescent lights and incandescent lights, in shaded or dimly light areas, etc. Some information should be gathered in twilight or at night.

Adaptations you might consider:
* Have the child shift to tactual signing. For example, when the lights are dimmed for a video tape, a child with peripheral field loss may need this support.
* Use area lighting. Lamps or overhead spotlighting on the person communicating can be very helpful. Position the light so that shadows don't fall on the signer's hands or face.
* Use visors, hats, and sunglasses to reduce glare. For students with Usher Syndrome or other visual conditions, glare is a big obstacle.
* The person signing should not stand with their back toward a light source (e.g., standing in front of a window).
* Information from overhead transparencies should be provided in another form.

5) Does the visual background affect the child's comprehension?
Professional sign language interpreters wear dark solid colors when interpreting because it provides good contrast to their hands. This makes their signs clearer and easier to read.

The child with visual impairments has to work harder to pick out visual information when there is a "busy" visual background. Watch to see if the child's comprehension skills increase or decrease when decoding signs against different visual backgrounds.

Adaptations you might consider:
* Dressing in dark, solid colors might make signs easier for the child to discriminate. If the teacher's wardrobe does not contain many dark, solid colors, they might consider wearing a smock of a dark, solid color.
* Selecting the best color to improve background contrast. (e.g., Some children may be able to see better with purple as the background color rather than black.)

6) Does the student have skills to advocate for the modifications he needs?
Many children, even at a very young age, will let you know when they can not see what you are signing. They may pull away from tasks or refuse to look. The older child may move your hands so they will be in his field of vision or become critical of your signing. Note how well the child can assess his ability to see in any given situation and how well he can communicate visual difficulty to others. Ultimately, only the individual with deaf-blindness knows what really aids him in accessing communication and he must be able to advocate for these adaptations throughout his life.

Adaptations you might consider:
* Work individually with the child to teach him to tell you what adjustments he needs.

7) Can a student follow signed conversations in group settings?
Group instruction poses different demands on a child's functional use of vision than when he is in one-on-one situations. In a group lesson a teacher may start signing a sentence directly to the student at 6"-12" and then turn to another child to finish the statement. Suddenly the teacher's hands have moved to a distance of 30" from the child. When this occurs, the student with a vision loss misses part of the sign(s) simply because it has moved out of visual range.

The distance and angle of the manual communication continually changes as different people in the group take part in the discussion. The student is constantly having to locate the person signing and refocus to see what is being signed. He may even need to physically reposition himself to bring that person into view.

Taking the additional time to provide even the most basic adaptations necessary to include the child with deaf-blindness will frequently break up the momentum of a group lesson. You may know the child needs additional time to study pictures, needs other people to sign more slowly, or has trouble tracking the movement of hands. However, consistently making these changes, while conducting group instruction, may be impossible. As a result, it is easy to deny the same level of instruction to the child with deaf-blindness.

Adaptations to consider include:

* If the child is included in group activities, additional staff may be needed to assist in informational access.
* Point to the person who will sign next, and allow the child time to visually locate them.

Interviews

After your team has observed the child in the educational setting, share your observations. Be sure to interview team members who have the most experience with the child in communicative interactions. This should include such people as the family, the educational interpreter, instructional aide, etc.

Don't forget to talk with the student. In many cases he may be the best person to tell the team about problems he is having. However, it is important to remember that some children are not aware they are missing information in certain situations.

Once you have formulated a theory about how the child is using his vision, you can devise some situations to test your theory. The results may suggest the specific adaptations you want to try. These adaptations are likely to be very individualized not only from child to child, but from situation to situation for an individual child. This occurs because one individual may be effected by different lighting conditions, the degree of familiarity with a situation, the number of other visual demands being made, etc. If the child has a progressive or a fluctuating vision loss, then the adaptations he requires may also vary over time or within a short period of time.

ADDITIONAL QUESTIONS

After addressing the first group of questions, conducting interviews with staff and family, and reaching some conclusions about the child's visual functioning, we often find that we need to ask some additional questions.

8) Would the student benefit from supplemental experience work to assist in understanding the concepts behind the signs?

Children who are deaf or hard of hearing have a wealth of incidental visual information to serve as a basis for language. This may not be the case for a child with deaf-blindness. Significant amounts of this critical information are distorted or missing altogether for a child with a concurrent visual loss. For example, this child may never be able to see a bird flying or sitting in a tree, or for that matter see a "bird" at all. Showing him a picture or giving him a sign for bird assumes he knows not only what the symbol represents, but has a concept of "bird." This may not be true for him.

New information should not be introduced on a picture or sign level if the child does not have a firm experiential base to relate to the picture or sign. Even though he may have the ability to understand or remember information, if he is not getting all the information in the first place, it is virtually impossible for him to understand. This is an access issue. Children with deaf-blindness need extensive, organized experiences with real objects and actions before they can truly understand pictures, fingerspelling, or signs which represent these objects and actions. Their sensory losses have denied them this experience.

Even if the child has a good experiential base, there still may be a need for supplemental experience work. Demonstrations and modeling are used extensively with deaf or hard of hearing students. If the student cannot see the demonstration, he needs to do the action himself. For students with field restrictions, who can see the demonstrations, watching demonstrations while simultaneously attending to signing requires rapid shifts of gaze. In the process, parts of information from both sources may be lost. Objects may need to be examined tactually and visually before they can be recognized when viewed at distance. The child with acuity loss may also miss information or receive distorted information. Class demonstrations may prove equally difficult for him.

Adaptations you might consider:

* Provide supplemental experience work to build his overall conceptual base.
* Allow the child to go through the demonstration

individually before he participates in the demonstration with the group.

9) Is the child's vision such that he would benefit from the technique of coactive signing when learning new signs?
Coactive signing is a technique which teaches expressive sign skills to students who are visually impaired and unable to see the instructor model the sign. When teaching a sign, the instructor takes the students hand(s) and helps the student form the sign correctly. This technique can also be used with students who have visual perceptual problems because these children may not be able to learn to produce signs just by watching others. While coactive signing teaches the child to make signs, he will still need to learn to read signs when others produce them. Therefore, it is important to give the child an opportunity to see (or tactually read) you make the sign if they are to learn the sign receptively.

The SKI*HI Institute has produced 12 videotapes which help family members and professionals use coactive signing effectively. (Watkins, 1991)

10) Does the child initiate or benefit from (tactual) tracking?
(Tactual) tracking when used in reference to signing occurs when the person with deaf-blindness places his hand(s) on the wrist(s) area of the signer. This technique enables a person with a visual impairment to know where the signer's hand is moving so that he can direct his gaze accordingly. He may also get enough information from the plane or general location of the hand to recognize the sign without seeing it clearly. Tactual tracking can also be used in conjunction with the other adaptations mentioned in question #1.

Some children initiate this technique on their own. This is usually an indication that they need more information than they are getting visually. Sometimes this can be a tip-off to a field loss. (Tactual) tracking should be on this child's lists of strategies since there are some situations where the strategy of moving further from the speaker is impractical (e.g. sitting next to a friend on the bus when his optimum distance for viewing is 4 feet). The child should be allowed to shift to (tactual) tracking when he chooses. In some instances, this technique will need to be taught to the child.

11) Does the child initiate or benefit from tactual signing?
Note: This is an abbreviated discussion of the important issues involved with tactual signing. Tactual signing, a receptive skill, should not be confused with coactive signing which is used to teach expressive signing.

Tactual signing is used by a person who understands sign language but cannot read signs and fingerspelling visually. To receive information, "the deaf-blind person places one or both hands on the hand(s) of the signer in order to read signs and fingerspelling through the tactual sense. (It is) ...a direct adaptation of a communication system originally intended for vision...to the tactual sense." (Reed, et al 1995.) Using tactual signing is a receptive skill.

Tactual signing is typically used with the student who is blind. For students who learn signs visually and then undergo a significant vision loss, there will be a process of relearning the signs tactually. Signs feel different than they look. There also may be emotional issues to face in switching to tactual sign because it is an admission of vision loss. This is an extremely stressful change for a person who is hard of hearing or deaf.

In order to be a skilled reader of tactual signs a person must do more than just learn how the signs feel. He will need to learn how to place his hands to get the most information without interfering with the speaker's ability to sign. Typically, the student uses both hands in the beginning. As his skills increase or if he is very familiar with his partner, he may use only one hand. The student will need to "keep it light" in terms of how much weight he puts on the hands of the person who is signing to him. The partner can fatigue very quickly, and over time, injuries like Carpal Tunnel Syndrome can occur if adequate breaks are not allowed. The person with deaf-blindness may also become fatigued because holding his hands in place for long periods of time is tiring, and reading signs tactually takes a great deal of concentration.

Much of the information conveyed in sign language is expressed through facial expressions, eye gaze, a slight shrug, etc. With tactile signing, every attempt should be made to find alternate ways to convey the meaning tactually.

When conversing with or interpreting for a person who is deaf-blind, additional environmental information should be supplied along with the conversation or lecture. For example, who is in the room, a description of the furnishings, an unexpected noise, etc. Without this information some comments may not make sense if people are referring to things that the deaf-blind person cannot see or hear. Have each person say their name before making a comment and provide the interpreter with a seating chart which contains the names of the others in the group.

While tactual signing is used by individuals whose vision loss is total, it is also used by people who have vision but are not able to see the signs and fingerspelling clearly enough to understand them. If a student with low vision initiates this modification, it should be respected as an attempt to gain necessary information. The child should be given the opportunity to receive signs tactually. Some students may need to use tactual signing in some situations and not in others. For example, a student may need to rely on tactual signs in very dim light, but be able to get by without it under good lighting conditions.

In some instances, utilizing tactual signing can allow a child to follow a discussion with his hands while he uses his vision to regard the item or situation under discussion. He doesn't have to choose what to look at. When a child becomes more sophisticated in signing, having to read longer sentences, he may no longer be able to get by on his vision alone. He may move to tactual signing because of a change in the level of demand upon vision. In another student, self-initiation of tactual signing could indicate a problem with the child's vision.

Using tactual signing will affect the pacing and design of the lesson. For example, if there are materials used in conjunction with the lesson, the child must have time to examine the materials before he can return his hands to his partner. If a teacher is signing to other students, it will be difficult for her to stop and repeat everything she says tactually to the deaf-blind student. She must also convey any comments that the other students make as well as reading information from the board or overhead. Almost without exception an additional staff member will be needed to provide tactual support.

12) If a student will benefit from braille, are there English acquisition issues associated with students who are deaf or hard of hearing which should be addressed?

When determining whether print or braille should be used for a student who is deaf or hard of hearing, teachers will need to keep in mind that slow reading rates and problems with comprehension may be due to a difficulty in acquiring the English language. In many ways, these students' learning needs are similar to those students who are learning English as a second language. A change in literacy medium from print to braille may not improve reading performance for students experiencing language problems.

Techniques that might address this concern:

* The ability to fingerspell has been useful in supporting the learning of the braille alphabet.

* Generating stories and text based on the child's actual experiences or interests will help them understand the English represented by the braille.

* Modify the language level to match the child's ability to read and understand English.

13) Are there instructional strategies, materials, and tools typically used with students who are deaf or hard of hearing which may present problems for the students with deaf-blindness?

* Pointing, facial expressions, gestures, demonstrations, and modeling. These methods require shifting gaze from signs to some other reference.

* Sign cards and pictures of signs used to teach signs. If these are used it is important to determine the best presentation: color or black line drawings, high contrast, figure-ground clarification, perspective, etc.

* When working on the floor, teachers frequently place pictures or objects on the floor and then sign at chest level. Visual demands are being presented in two places and at two distances re-

quiring gaze shifting and refocusing.

* Holding two pictures or objects side by side and bobbing them up and down in a modification of the sign for "which". The child with a vision loss is faced with the problem of trying to interpret moving pictures.

* Captioned films/videos or computer aided real time (CART). A child with field restrictions or acuity problems could have difficulties in reading the print.

* TDD (telecommunications device for the deaf) may need adaptions to the keyboard such as an enlarged display. A device such as the Telebraille may be appropriate if the student is a braille user.

14) Are there modifications to standard interpreting arrangements or signed classroom instruction which need to be addressed?

Note: this is an abbreviated discussion of the important issues involved with appropriate interpreter services.

It is possible that a person with deaf-blindness may need a completely different interpreting arrangement than other hearing impaired students in the same classroom. Even in an environment where everyone is signing, you may need additional support. For example, at a recent conference we had four participants who requested sign language interpretation. One of the participants could see the platform interpreter who stood by the speaker. Two of the participants required a tactile interpreter. The fourth person used a close vision interpreter. Three different interpreting arrangements were needed simultaneously, in order to make the information accessible to all participants.

Adaptations about interpreter arrangements:

* Platform interpreting. The interpreter is positioned near the speaker. They can be too close or too far away from the student with deaf-blindness.

* Small group interpreting. The interpreter sits within two or three feet of a small group of students. This is an adaptation provided for those whose vision prohibits them from seeing a platform interpreter.

* Close vision /(1 on 1) interpreting. This type of interpreting is provided when an individual's vision loss requires specialized placement of the signed information. This is frequently the case when a person has restricted visual fields or other visual impairments that require signs to be delivered within a particular space or from a particular distance. This also occurs when a person needs to use tactual signing.

* Visual descriptions. When interpreting for a person who is deaf-blind (or conversing with him), the interpreter includes descriptions of what he can't see or hear.

* Tactual Interpreting (see question #11)

CONCLUSION

Making the appropriate modifications and adaptations for a child with deaf-blindness is critical to their educational achievement. If his unique needs are not met, the child, no matter where he is placed, is in the most restrictive environment. He is cut off from any opportunity to learn. Unfortunately, these supports are not always easy or inexpensive to provide.

By conducting a thorough assessment of the child's visual functioning in accessing manual forms of communication you can determine the supports that are necessary. This will help you and your team to develop the type of programming which has the most benefit for the child educationally and make that program accessible to him.

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CLASSIFIEDS

DBMAT
Annual Fall Conference and Family Retreat Weekend

October 13-15, 1995

Camp John Marc Meyer
Meridian, Texas

There will be organized activites for **all** members of the family with experienced childcare providers available.

An announcement and registration form will be in the next issue of "In Touch", the newsletter of DBMAT

If you would like more information about this special weekend, please call DBMAT Parent Connection at (214) 287-1904 (voice/fax).

PATH Statewide Conference

Family Matters II: Look Out for the Future

October 6-7, 1995

San Antonio Airport
Hilton and Conference Center

There will be 36 breakout sessions addressing the needs of parents, professionals, and educators. Topics will cover behavior issues, ADHD, Section 504, stress management, communicating with lawmakers, rights and opportunities ...and much more

If you would like to receive a brochure or more information about this valuable conference, please call PATH at 1-800-866-4726

Sixth Annual Symposium for Teachers of the Visually Impaired: Helen called her "Teacher"

October 6-7, 1995
Austin, Texas

Sponsored by:
Texas School for the Blind
and Visually Impaired

Topics:
- •Quality Programs for Students with Visual Impairments
- •Babies and Toddlers
- •VMI (Visually & Multiply Impaired)
- •LMA (Learning Media Assessment)

Registration is $35

For more information contact
Laura Baker, TSBVI Outreach,
at (512) 206-9268

Other Workshops Sponsored or Co-Sponsored by TSBVI

"Through Your Child's Eyes" a workshop for parents of children with visual impairments will be held September 16 - 17 in Austin. For more information call Sue Currey, TSBVI Outreach, at (512)206-9224 or Kitty Ramsey, Region XIII ESC, at (512)929-1353.

"LOOKING AHEAD: *transitions to adulthood experienced by students who are deaf-blind*" will be held in Austin, on September 23, at the Austin Marriott at the Capitol. A registration form is enclosed in this issue of P.S. NEWS!!! Contact Beth Sánchez, at (512) 206-9103.

INSITE Training will be held in Corpus Christi, November 13-15 (part 1) and December 6-8 (part 2). For information contact Joyce West, Region 2 Education Service Center, at (512) 883-9288, ext. 2246 or Gigi Brown, TSBVI Outreach, at (512) 206-9272.

WORKSHOPS AND CONFERENCES

Supported Employment: It Takes the Whole Community will be held:

August 16-17 in Dallas
August 21-22 in Austin
August 24-25 in Houston

For more information, call the Texas Planning Council for Developmental Disabilities at (512) 483-4080 (V) or 483-4099 (TDD).

Project P.O.D.E.R. hosts the **7th Annual Texas Fiesta Educativa Conference - A Bilingual/Bicultural Conference for Families with Children with Disabilities and for the Professionals Who Serve Them** in San Antonio, Texas August 25-26, 1995. For information, call Project P.O.D.E.R. at 1-800-682-9747.

TCB and Region 20 Education Service Center will host **"HELP: Helping to Educate for a Lifetime of Possibilities"** in San Antonio. Contact Kathleen Ford at (210) 299-2400 for information.

SKI*HI Training will be held at Region XIII Education Service Center September 18-21, 1995 (part 1) and January 29-31, 1996 (part 2). For more information call David Ramirez at (210) 735-1214 or Barbara Talamantez at (210) 661-3354.

The **Discovery '95 NAPVI / Illinois Low Vision Conference** will be held October 12-14 in Chicago, Illinois. For more information contact the National NAPVI office at 1-800-562-6265.

"National Conference on Active Learning: The Methodology and Philosophy of Establishing Active Learning Environments for Infant, Preschool and Multi-Impaired Blind and Visually Impaired Children" November 13-17 in Seattle, Washington. For more information, call Sherry Raynor at (517) 333-1725.

Getting in Touch with Literacy: A National Conference Focusing on the Needs of Individuals with Visual Impairments will be held in Austin, December 7-10. For more information contact call Phil Hatlen at (512) 454-8631.

BONDING AND RELAXATION TECHNIQUES (BART)

Touch is a basic human need and research studies point to the importance of touch in the healthy growth of infants and children (Fields, 1992). BART is based upon Vimala McClure's Infant Massage parent education program which was adapted by Evelyn Guyer, RN, BSN, seven years ago, to address the needs of infants, children and older individuals with special needs. The techniques are being used in nine states, Canada, and four European countries.

One of the major goals of the BART program is to reduce stress levels in both parent/caregiver and child, as well as to empower the parent and foster respect for the child. Through an individualized plan of stroking, BART addresses the many physical, emotional and sensory needs of children with, or at risk for developmental delays. Other benefits include bonding and attachment, improved communication and a feeling of greater love and security-benefits realized by both parent/caregiver and child. Increased body awareness of the child himself is especially important if physical disabilities exist, such as visual or hearing impairments or impaired motor skills. Enhanced respirations, gastro-intestinal functioning, sensory integration and behavioral organization have also been seen to improve.

The BART program is a training course for professionals who work with parents and families of children with special needs. In an intense two-day course, professionals from schools, agencies and Early Intervention Centers learn the skills to become parent educators. These BART instructors are not 'hands on' practitioners. Only the parents stroke their children.

BART is recognized as a valuable, specialized program by the International Association of Infant Massage (IAIM). After the course, the BART instructors are certified to conduct individual or group sessions with parents and their children, teaching parents/caregivers the specific stroking plan for the child.

BART Training will be held in Texas:

October 23-24, 1995 - El Paso
October 25-26, 1995 - Edinburg
October 27-28, 1995 - Houston

Tuition is $199.00

For more information, contact Evelyn Guyer at (716) 652-2763

RESOURCES

National Family Association for Deaf-Blind Supporting Persons who are Deaf-blind and Their Families is a national network of families who focus on issues surrounding deaf-blindness. For information on how you can become a member of NFADB, call 1-800-255-0411, ext. 275.

There is a new support group for parents of children with feeding tubes. The Gut Instinct goal is to provide understanding, encouragement, and information to families of children with gastrointestine (GI) disorders. For information, call Jan Williams at (210) 521-9743.

The Texas Department of Insurance has published a 12-page booklet explaining the rights of Texans with disabilities to fair and equal consideration for insurance coverage under the law. To get a free copy of "What Texans with Disabilities Should Know About Insurance" call 1-800-599-7467.

Families seeking respite services in any area of the U.S. now have the **National Respite Locator Service** available. The service operates a national database of organizations providing respite throughout the country. For more information, call 1-800-773-5433.

PARENT-TO-PARENT

Parents of children with visual impairments in the San Antonio area may be interested in joing the Alamo Area NAPVI. NAPVI is an organization run totally by parents of children who are blind or visually impaired. For more information, write to Alamo Area NAPVI, 8417 Bear Tree Circle, San Antonio, Tx. 78255.

Parents in the Lubbock area have the opportunity to be a part of a support group to share information, concerns and compassion related to having a child with special needs. Contact Heaven's Very Special Children through Methodist Children's Hospital in Lubbock.

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Escuela de Texas para los Ciegos & para Personas con Limitaciones Visuals
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Agosto 1995

Vol. VII, No. 3

ESQUINA DEL EDIOTR

La edición de julio de P.S. NEWS!!! llega tarde debido a nuestras ocupaciones en la organización del Simposio de Sordoceguera, patrocinado por TSBVI *Deaf-Blind Outreach* = Servicios de Extensión a los Sordociegos, que tuvo lugar del 23 al 24 de junio de 1995, aquí en Austin. Tardamos en la preparación de esta edición para poder compartir con ustedes la información del Simposio.

Durante la primera mañana del Simposio, 42 miembros de familia y 119 profesionales escucharon el discurso inaugural de la Directora de Extensión, Cyral Miller (páginas 3-5). Inmediatamente después de su discurso, se presentaron tres estudios de casos de niños que tienen sordoceguera.

Robbie Blaha, Especialista en Educación, de *Deaf-Blind Outreach* y Ann Bielert, Instructora de *Alief ISD* = Distrito Escolar Independiente de Alief, nos presentó a Larissa Lepik. Larissa, nieta de Tomás y Gretta Lepik, tiene once años de edad. Su sordoceguera ocurrió a consecuencia del síndrome de rubéola congénita. Robbie y Ann comentaron el procedimiento usado para desarrollar e implementar su programa en un aula regular de escuela primaria. Con Ann su instructora, Larissa ha logrado muchas metas, entre otras, el uso de una caja de calendario para organizar su día, aprender a ser más independiente para hacer sus tareas, y usar y cuidar sus aparatos adaptables (gafas, aparato para oír, sistema FM, etc.). Sus habilidades para comunicarse también mejoran día a día.

David Wiley, especialista en Transición de *Deaf-Blind Outreach*, Delinda Henry, madre de Jamie Jackson y Sharon English, quien fue maestra de Jamie en TSBVIEl, presentaron el segundo estudio. Jamie, un joven de 21 años de edad profundamente sordo y totalmente invidente, ha tenido grandes problemas de comportamiento los cuales le crearon barreras para aprender y fomentar las relaciones interpersonales. En los últimos años se le diagnosticó desorden bi-polar y ahora toma medicina, la cual parece ayudarle mucho. Además su programa se cambió para orientarlo hacia las habilidades de comunicación, fomento de las relaciones y las maneras de elegir. Jamie comenzó a mostrar un gran progreso. Parece capaz de valorar a la gente con quien se asocia. Ha participado en el entrenamiento para el trabajo en varios sitios en la comunidad donde se le aprecia como trabajador. Jamie y su mamá se están preparando para su transición del lugar de estudio a su vida adulta en un ambiente comunitario.

Linda Hagood, especialista de Educación de *Deaf-Blind Outreach*, y Mark O'Dell, padre de Breezy O'Dell, presentaron el tercer estudio. Breezy es una niña de seis años de edad, que tiene significativa pérdida de la visión y del oído como consecuencia del síndrome de KID. Ella ha tenido muchos problemas de salud por causa del síndrome, pero a pesar de todo esto, se mantiene muy alerta, vivaz y encantadora. Breezy está en un aula de clases para las personas que tienen problemas del oído, en ISD, Amarillo, y recibe la mayor parte de su instrucción en lenguaje de señas. Ella recibe apoyo individual de parte de un intérprete educativo. Debido a que su pérdida de la visión puede ser progresiva, ella debe adquirir unas bases fuertes en lenguaje a la mayor brevedad. Los retos que su equipo educativo enfrenta son: adaptar las estrategias de enseñanza, el personal y los materiales.

Durante el día, los profesionales y los familiares tuvieron la oportunidad de visitar, compartir experiencias e ideas, y conocer a otras personas involucradas en la vida de personas con sordoceguera. Muchas de las familias que estaban en el Simposio nunca habían conocido a otras familias con un niño sordociego. Para ellos, el conocer a otros padres o miembros de la familia, fue lo mejor del fin de semana.

El sábado por la mañana los participantes tuvieron la oportunidad de seleccionar la jornada del día. Linda Hagood, Bárbara Talamentez, Consejera de Padres para ISD en el Noreste de San Antonio, y Dottie Haley, Intérprete en el Condado de Travis, hicieron una presentación sobre los Servicios para los Sordos, "Uso del sentido táctil: Consideraciones en el desarrollo de la comunicación para estudiantes sordociegos que aprenden por medio del tacto" ofrecieron un popurrí de información sobre el uso de símbolos táctiles, el uso de señales táctiles y señas coactivas, y el papel del intérprete.

Jim Durkel, especialista en educación de Extensión para Sordociegos y audiólogo, presentó "*Using the Auditory System: Issues for the Child with Deaf-Blindness.*" = El Uso del Sistema Auditivo: Temas para un Niño Sordociego. Esta sesión dio información básica sobre cómo funciona el sistema auditivo y resaltó la importancia de un buen ambiente para escuchar y de la amplificación apropiada para el niño sordociego. Jim también discutió diferentes tipos de evaluaciones audiológicas y explicó los beneficios de cada una.

La plática "*Using Low Vision: Considerations in Developing Skills in Students Who are Hearing Impaired with Functional Vision*" = Uso de la Visión Limitada: Consideraciones en el Desarrollo de Habilidades en Estudiantes con Limitaciones del Oído que Tienen Visión Funcional, se canceló a última hora y se sustituyó con un festival de cine. Este era un tema en el que yo tenía especial interés y decidí pedirle a Robbie Blaha que resumiera esa presentación en un artículo para P.S. NEWS!!! Este artículo lo puede encontrar en las páginas 11-19.

La sesión final del Simposio fue "la mejor parte". Nosotros tuvimos el privilegio de tener a tres maravillosos oradores que aportaron gran experiencia al tema "*Deaf-Blind Services* = Servicios a los Sordociegos en la década de los '90". El primero de los oradores fue Michael Collins, uno de los presidentes de la Coalición Nacional sobre Sordoceguera. Mike compartió una historia breve sobre la educación de estadounidenses con sordoceguera y dio una visión desconsoladora del futuro de los servicios a las personas con sordoceguera en este país (ver artículo en la página 3). Sus comentarios se encuentran en las páginas 14-15.

Después escuchamos a Jack Earwood, especialista en Sordoceguera de la Comisión de Texas para la Ciegos. Jack compartió información sobre los recursos disponibles para las personas con sordoceguera, desde el punto de vista de un profesional y de una persona con el síndrome de Usher. Jack contó lo importante que es el apoyo de su esposa, su hija y de sus amigos. El habló sobre el ser identificado "lento" en la escuela y cuánto tiempo le tomó terminar el colegio porque él no tenía ni el apoyo ni las adaptaciones necesarias para tener acceso a la información. Acentuó la importancia de los defensores de las personas con sordoceguera; motivó a los profesionales y a las familias para que tomen parte en organizaciones como *Texas Deaf-Blind Association (TDBA) y Deaf-Blind Multihandicapped Association of Texas* (DBMAT); a que se conviertan en defensores de los servicios a las personas con sordoceguera.

Nuestro último orador fue Kim Powers, estrella de "*Kim's World*" = El Mundo de Kim, un programa para niños en *KALEIDOSCOPE*, la primera red en el mundo para personas que tienen alguna incapacidad, con sede en San Antonio. Aunque Kim es totalmente ciega y con graves problemas del oído tiene muchos deseos de vivir. Uno de sus muchos intereses es el paracaidismo. Kim habló sobre cómo fue su crecimiento siendo sorda, y el aislamiento que ella sintió hasta que fue a la Escuela de Texas para Sordos. Allí, por primera vez, ella estuvo en un mundo donde todos podían comunicarse con ella. El entusiasmo que Kim tiene por la vida y su profundo interés en comunicar sus experiencias al mundo, inspira.

Ahora, antes de que sigan leyendo esta edición, quiero que sepan qué acciones está tomando la legislatura estatal y federal y el gran impacto que probablemente va a tener sobre *Deaf-Blind Outreach*. El alcance completo del impacto no está claro hasta ahora. Estamos actualmente en las etapas finales de negociar el subsidio Federal CFR 307.11 que provee la mayor parte del dinero para nuestro programa. El resultado final de este proceso podría dar lugar a cambios significativos para *Deaf-Blind Outreach*. Esperamos poder compartir cualquiera de estos cambios con ustedes en la edición de octubre.

Acción de Alerta de la National Coalition on Deaf-Blindness

21 de julio de 1995

Como ustedes probablemente saben, la *House Subcommittee on Appropriations* le quitó $3.85 mil millones de dólares al presupuesto del Departamento de Educación. Especialmente, los programas discrecionales sufrieron más. El financiamiento bajó de $245 millones a $78.9 millones, un recorte del 69%. Estos recortes incluyen todos los fondos para la preparación de personal en educación especial.

Los servicios para niños sordociegos se retuvieron en $12.8 millones. Es importante entender que esto no significa que nosotros ahora estemos seguros, y tengamos garantía de este financiamiento. Estas cantidades ahora van al *House Appropriations Committee* el día primero de agosto, donde se aceptarán o se les harán cambios.

El Congreso entonces tomará el receso de agosto, y cuando se reúnan otra vez después del Día del Trabajo, la Cámara de Representantes en pleno votará sobre el presupuesto.

Parece que el Senado no comenzará el trabajo de apropiaciones hasta después del receso de agosto. Y luego el Senado y la Cámara se reunirán para discutir sus diferencias y acordar los artículos que serán financiados. La ley, entonces se enviará al Presidente para ser aprobada. Como ven, nosotros todavía tenemos mucho trabajo por hacer.

Debemos dar a conocer a los funcionarios del Comité de Asignación de fondos de la Cámara y del Senado que estos recortes van a afectar todos los programas discrecionales, y que nosotros necesitamos que continúen los $245 millones en programas discrecionales. Por favor, insista en su carta sobre la necesidad de los programas de preparación de personal.

Además: nosotros debemos prestar atención al lenguaje que se use en la ley IDEA cuando vuelva a ser autorizada. Debemos luchar para que nuestro financiamiento y nuestros servicios específicos para sordociegos sean protegidos allí también. El lenguaje de la ley podría afectar el recorte del financiamiento, porque esto daría como resultado que los fondos para los servicios de los sordociegos sean desviados para otros propósitos, entonces debemos prestar atención al lenguaje de IDEA.

En resumen, las acciones más específicas y útiles son las siguientes:

1. El *House Appropriations Committee* está programado para elaborar el presupuesto del Departamento de Educación el primero de agosto. Pídanle a la gente que llame pidiendo la restauración del dinero de los programas discrecionales.
2. *House Subcommittee on Early Childhood, Youth and Families* = Subcomité de la Cámara para Niños, Jóvenes y Familia, se reunirá el 26 de julio o el primero de agosto para redactar IDEA. Pídale a la gente que llame a pedir que no se haga ningún cambio en los servicios del Programa para Niños con sordoceguera. Recuérdeles que los niños y las familias necesitan desesperadamente estos servicios del Gobierno Federal, porque los estados frecuentemente no se dan cuenta de las necesidades que hay en este grupo de personas de tan baja incidencia en la población.

Llámenos al 617-972-7221 si tiene preguntas acerca de la situación y nosotros lo mantendremos informado, lo más que podamos.

Michael Collins y Joseph McNulty, Presidentes de la Coalición Nacional de Sordoceguera

Discurso Inaugural del Simposio 1995 sobre Sordoceguera

Nota del editor: La presentación fue hecha por la Directora de Extensión de TSBVI, Cyral Miller, a las familias y a los profesionales que asistieron al Simposio sobre Sordoceguera que tuvo lugar en Austin, Texas, los días 23 y 24 de junio de este año.

Me han pedido que hable sobre lo que he aprendido como resultado de los 5 años que he estado dirigiendo el equipo de Servicios de Extensión para Sordociegos. Tengo que confesar que entré como una "Persona con Visión" muy segura de mí misma, y creo que mi primer pensamiento fue que tenía el conocimiento y el entrenamiento de lo que consideraba un segmento de la población con problemas de visión. Ahora, mucho más humilde por mis años de trabajo con este equipo, quiero confesar que estaba equivocada. Pero he aprendido y quiero compartir este nuevo conocimiento.

1. La sordoceguera no es un sólo padecimiento y no describe a un niño. La variedad de estudiantes que nos piden que les ayudemos es sorprendente. Hay unos estudiantes que usan el lenguaje de señas y escriben los informes académicos a mano, otros que usan braille y señas táctiles, otros que usan gestos u objetos para comunicarse, y otros a quienes se les enseña con base en los estados de comportamiento de quietud, agitación o sueño. Hay algunos que son totalmente invidentes y totalmente sordos, y otros con mucho sentido sensitivo útil. Cuando se agregan los otros factores que definen a una persona, como la edad, el lugar, los intereses, la familia y los estilos de aprendizaje, tenemos una gran diversidad de gente dentro de la misma categoría de sordociegos.

2. La sordoceguera tiene su propias teorías, metodologías y profesionales. Hay un cuerpo definido de conocimiento sobre esta población y sus necesidades. Este conocimiento se ha desarrollado durante los últimos 150 años. Nosotros sólo hemos oído hablar de Helen Keller, pero hay un legado grande de gente que era sordociega, incluyendo a Laura Bridgman, Julia Brace, Helen Schultz y otros que se educaron en lugares diferentes y épocas diferentes, usando métodos distintos a medida que se han ido desarrollando y refinando.

3. La sordoceguera no es igual a otras incapacidades, ni un poco diferente, ni parecida a otras incapacidades. No es una suma de diferentes áreas de limitación, porque las limitaciones se "entretejen" (Hart, 1977) en la misma tela de la persona y frecuentemente no pueden clasificarse o mencionarse individualmente. Los maestros de las personas con limitaciones visuales no pueden simplemente trabajar con los maestros de las personas con problemas del oído para encontrar un programa apropiado. No es un proceso aditivo, sino más bien un proceso diferente. "Los problemas de aprendizaje que tienen los niños con limitación sensitiva doble son muy distintos a los problemas que tienen los niños con limitación del oído o de la visión. Los niños sordociegos necesitan educación y entrenamiento diseñado para satisfacer sus necesidades especiales" (Hart, 1977).

4. Los programas deben diferenciar entre los estudiantes sordociegos y otros. De alguna manera estos niños pueden parecerse a otros con otro tipo de incapacidades y capacidades. Hay adaptaciones que pueden tomarse de otros campos y que pueden funcionar bien para un niño sordociego y viceversa. Los sistemas calendario, por ejemplo, que pueden proveer un sentido de orden a un universo caótico, pueden ser sumamente beneficiosos para otros que necesitan tener una rutina. Pero todos los niños que usan calendario no usan el mismo tipo de calendario, ni tampoco usan el mismo tipo de dispositivo adaptable para obtener el mismo propósito o resultado. Yo pienso que muchos de los programas nacionales, han evadido este asunto, primero con la especialización en sordoceguera, después decidiendo que había tantos con incapacidades múltiples que la programación genérica más severa y profunda era apropiada, y ahora (espero) viendo que a pesar de las similitudes, los niños sordociegos necesitan algo diferente.

5. Las definiciones sobre la sordoceguera son complejas. La definición federal indica que un estudiante con limitaciones auditivas y visuales combinadas crea tan severas necesidades de comunicación y otras necesidades de desarrollo y aprendizaje que no se le puede educar adecuadamente en programas especiales de educación para niños con problemas del oído, o para niños invidentes, o niños que tienen incapacidades severas, sin la asistencia complementaria para atender sus necesidades educativas debido a estas incapacidades dobles que ocurren. Si usted no sabe lo que tiene que buscar, algunos niños parecen que son sordociegos. Se necesitan conocimientos de tipo específico para evaluar correctamente el estado de un niño sordociego.

6. Los niños sordociegos muchas veces no son atendidos por la gente que sabe sobre sus necesidades. El nivel de estudios superiores para maestros en este campo comenzó en 1956, en la Universidad de Boston. Antes de esto, el trabajo lo hacían maestros sin entrenamiento y personas que se dedicaban a aprender en el trabajo, o mediante cursos intensivos de verano. En 1960, se iniciaron más programas de entrenamiento como resultado de la epidemia de rubéola, pero todavía hay pocos programas que entrenan maestros específicamente para esta población, y pocos estados donde se requiere o se reconoce este certificado. Si usted llama a pedir ayuda al centro de servicio de educación regional de su área, se dará cuenta que no hay especialistas contratados para dedicarse a las personas con sordoceguera. No hay maestros locales con el entrenamiento específico que se dediquen a los casos exclusivamente de estudiantes sordociegos. Siempre ha habido escasez crónica y grave de maestros entrenados para estos estudiantes.

7. La mayoría de los programas y maestros que atienden a los estudiantes sordociegos todavía están aprendiendo mediante entrenamiento en el trabajo. A pesar del conocimiento general de los sordociegos que se aplica a cada niño de una manera singular dependiendo de sus propias necesidades, la mayoría de los maestros se conforman con tomar sólo 1 ó 2 días de cursillos para la mayor parte de su aprendizaje formal. Otras pocas profesiones tienen que confiar en un método para diseminar información práctica. Ustedes que trabajan, viven y aprenden sobre la sordoceguera para comunicarse, conocer y compartir su información con otros, tienen una gran responsabilidad porque esa es una manera inadecuada, pero es la única para comunicarse en este campo.

8. La sordoceguera tiene una incidencia MUY baja en la población. En Texas, casi no hay distritos donde haya más de uno o dos estudiantes sordociegos. Es difícil conseguir personal con conocimiento y entrenado en el campo, cuando realmente sólo va a trabajar con un estudiante. En muchos casos, el estudiante está allí por un tiempo corto y se va, y no vuelven a tener más estudiantes por varios años.

9. No hay muchos recursos cerca para los niños sordociegos. Antes de 1963 había en el país 7 programas de residencia para niños, que atendían a 125 niños sordociegos, y otros 150 fueron matriculados en programas públicos o privados. Con el aumento de los bebés con rubéola el Título VI-C de la ley de educación elemental y preparatoria generó centros modelo en toda la nación. Los primeros centros regionales fundados en 1968, desarrollaron servicios para la evaluación, el cambio, la orientación, la educación y la consulta a los padres, los maestros y otros interesados. Se le dio énfasis a los proyectos de asistencia técnica como el equipo de Servicios de extensión para Sordociegos, aquí en Texas. Ahora hay motivo de preocupación de si este nivel de asistencia especial seguirá recibiendo fondos a nivel estatal o federal.

10. La clave para comprender la sordoceguera es entender que la comunicación lo es todo. Como resultado, ACCESO al aprendizaje, a la información y a la interacción con los demás, es el punto principal. Yo he aprendido que con entrenamiento, es posible determinar cómo se puede ayudar a un adulto o a un niño sordociego a desarrollar sistemas de comunicación que den acceso a todas las riquezas del mundo. Creo en la importancia de dedicarles a estos niños especiales el tiempo y la energía, la devoción y el cuidado, para encontrar el camino al mundo.

Espero que este simposio les ayude a aprender algunos puntos específicos, y que se puedan llevar algún conocimiento especial para aplicarlo con sus hijos y estudiantes. Nosotros necesitamos comunicarnos ahora que están aquí y después de que se vayan. Espero con mucho interés poder pasar los próximos dos días aprendiendo y hablando con cada uno de ustedes.

Referencia:

Lowell, E.L. & Rouin, C. C. Eds. (1977). Training of personnel. *State of the Art: Perspectives on Serving Deaf-Blind Children*. Sacramento, CA: California State Department of Education, pages 238-245.

Asuntos sobre educación: La sordoceguera en la década de los 90

Resumen de una presentación hecha en el Simposio llevado a cabo en el año 1995 sobre la Sordoceguera

por Michael Collins, Presidente de la Coalición Nacional sobre Sordoceguera

REPASO DE LA HISTORIA RECIENTE

Durante las últimas dos décadas nuestros servicios para las personas sordociegas han cambiado notablemente. En la década de los 70, vimos la creación y el desarrollo de una red multi-estatal de centros regionales para niños sordociegos. Estos centros facilitaron una red nacional de comunicación entre las personas que atendían a esos niños, a la vez que crecían en número y organización. El personal contratado tenía entrenamiento específico en sordoceguera, y ofrecían entrenamiento y asesoría continua a los programas locales, y además producía muchas publicaciones y videos de entrenamiento, disponibles a nivel nacional.

Pero lo más importante era que los Centros Regionales tenían la responsabilidad de organizar los programas de servicio directo para niños sordociegos, antes de la promulgación de la legislación sobre educación obligatoria. Como resultado, durante los años 1970 a 1975, la mayoría de los estados había organizado varios programas especializados para los sordociegos dentro de las escuelas residenciales, instituciones estatales para las retardados (como se conocían entonces), y muchas escuelas públicas. Surgieron muchos "programas para los sordociegos". Algunos de nuestros estados más grandes, como California y Texas, tenían aulas para niños sordociegos a través de todo el estado, dentro de los sistemas escolares más importantes.

Sin embargo, estos programas eran casi todos en ambientes aislados o eran principalmente clases aisladas dentro de una escuela pública. Otro problema era que no todos los niños del estado eran atendidos por estos programas especializados. Antes del P.L. 94-142, estos programas podían escoger a los estudiantes en las admisiones. Los niños que no eran admitidos en estas clases eran atendidos en otros programas genéricos para niños con otras incapacidades, o no estaban en ningún programa educativo. El personal de los Centros Regionales tenía la responsabilidad de apoyar, desarrollar y asesorar los programas especializados para los sordociegos dentro de su región; también tenían un gran número de consultas de niños que no estaban en ningún servicio especializado.

Otra característica importante de esta década fue el establecimiento de programas en las universidades para preparar personal. Los programas para entrenar maestros se iniciaron principalmente con el apoyo federal (Campbell, 1976). Estábamos educando anualmente a más de 100 maestros con entrenamiento específico. Mediante los Centros Regionales, los graduados de estos programas fácilmente trabajaban enseñando a los niños sordociegos en toda la nación.

Durante esta época, no solamente había más maestros sino que estos podían tener trabajo relacionado con su entrenamiento. Un maestro entrenado podía conseguir un trabajo para enseñar a niños sordociegos en cualquier estado de la nación. Además, con un poco de experiencia, ellos podían ocupar las posiciones para especialistas en los Centros Regionales, Departamentos de Educación del Estado y Universidades. Teníamos mucha gente para escoger nuestros futuros líderes. Como consecuencia, muchos de nuestros estados tenían personal en posiciones de liderazgo que tenían entrenamiento y experiencia directa enseñando a la población (Campbell, 1976).

¿Cómo fue la instrucción durante estos años? Bueno, muchos de los niños recibían enseñanza en clases independientes para niños sordociegos. Un maestro y varios asistentes les enseñaban de 4 a 6 niños. La instrucción por lo tanto tendía a ser en clases con una proporción baja de maestro-estudiante. Frecuentemente el maestro tenía entrenamiento para enseñar a niños sordociegos o niños con otras incapacidades sensoriales múltiples. Cuando el maestro no tenía entrenamiento, sabía que había aceptado trabajar con una clase de niños con sordoceguera, y por lo tanto se preparaba participando en todas las actividades de entrenamiento posibles, leía sobre las técnicas usadas con la población, y gradualmente iba adquiriendo habilidades para enseñar.

Las instrucciones en muchos programas se concentraban en el desarrollo, con un enfoque hacia la enseñanza académica o "pre-académica". Predominaban la enseñanza del lenguaje, habilidades cognoscitivas, lectura, escritura, matemática y el desarrollo sensorial, y en muchas escuelas la enseñanza de estas cosas era buena. Los maestros sabían revisar los aparatos auditivos del niño, sabían distintos lenguajes y cómo enseñarlos, podían enseñar el braille cuando se necesitaba, podían efectuar el entrenamiento auditivo, utilizaban las formas apropiadas de evaluación, implementaban los currículos para estimular el uso de la visión residual y tenían la capacidad para enseñar a los niños a usar estas habilidades en situaciones de la vida cotidiana. La enseñanza de las habilidades de la vida diaria era comúnmente bien integrada al currículo.

En algunos lugares se le daba mucha importancia al contenido académico y se descuidaba el currículo funcional; se enseñaban algunas habilidades básicas diarias mientras que a otras habilidades prácticas no se les daba importancia. Frecuentemente las actividades no eran apropiadas a la edad, los adolescentes tenían que hacer actividades de niños. Los elementos de selección y autodeterminación no se encontraban en los currículos. El entrenamiento vocacional no existía en algunas escuelas y en otras se orientaba hacia la preparación para el trabajo supervisado. En resumen, mucho de lo que llegó a ser el último adelanto en la instrucción de la década de los 80, generalmente no se tuvo en cuenta (Snell, 1987).

SITUACION ACTUAL DE LOS SERVICIOS EDUCATIVOS

Nuestra filosofía de la educación de niños que tienen alguna incapacidad ha cambiado desde 1970. Hemos cambiado la educación dirigida únicamente en instalaciones aisladas a los servicios integrados en la comunidad local. Hemos cambiado los servicios de la centralización a la descentralización, para que estén disponibles en la comunidad para cada niño. El currículo funcional apropiado para cada edad ha reemplazado mucho la enseñanza académica. La colocación y entrenamiento vocacional es ahora vista como un aspecto clave en el currículo escolar. Los servicios que eran muy especializados para atender incapacidades específicas del niño, se cambiaron haciéndolos más generales para todos los niños.

Estas tendencias generales en la educación especial han tenido gran impacto sobre la manera como los niños sordociegos se educan. Lo común hoy en día es que al niño se le enseña en su comunidad; sus compañeros son niños con limitaciones múltiples, o sin limitaciones; su maestro no tiene ningún entrenamiento específico para los sordociegos; una persona entrenada puede dar asesoría en el aula mensual o anualmente; sus clases se enfocan en muchas habilidades funcionales, pero son débiles en la enseñanza académica, en habilidades sensoriales y en desarrollo del lenguaje; a medida que se acerca a la adolescencia, él tendrá probablemente un programa razonable de entrenamiento vocacional, dependiendo de la comunidad donde vive; puede que sus padres no sepan qué hacer con él en la casa, o que necesiten una persona con conocimientos para que los aconseje.

Nosotros ofrecemos un nivel bastante alto de asistencia técnica mediante nuestro programa nacional para niños sordociegos. Dentro de cada estado, los centros individuales y multi-estatales para niños sordociegos tienen como función principal dar la asistencia técnica. El proyecto de asistencia técnica llamado TRACES ha sido un buen apoyo en todos los estados en el esfuerzo por mejorar los servicios para los sordociegos. *Helen Keller National Center's Technical Assistance Center* cumple una función similar para los estudiantes en la edad de transición. Estos dos proyectos patrocinan entrenamiento a nivel nacional, y publican boletines con buena información en el campo. Similarmente, el proyecto *American Foundation for the Blind*, que presta cintas de entrenamiento y módulos para aprender comunicación y movilidad será un recurso maravilloso para todos los que tenemos el trabajo de proveer entrenamiento básico continuo. Ahora también tenemos un centro nacional de información que se está desarrollando de modo que los recursos y la literatura importantes sobre sordoceguera sean catalogados y fácilmente accesibles a todos.

Gracias a la promulgación de P.L. 94-142, nosotros ahora vivimos en una era en que todos los niños reciben servicios educativos. Ya no tenemos que ver a los niños sordociegos sentados en sus casas sin enseñanza debido a la distancia, escasez de financiamiento o rechazo.

El movimiento de integración ha causado definitivamente una dispersión mayor de niños sordociegos. Mientras que antes se encontraban en grupos más concentrados, debido al gran número de programas especializados, ahora se encuentran recibiendo servicios en mayor número de escuelas en un área geográfica más grande.

La dispersión de la población hace que los trabajos del Coordinador del Estado y del Consejero sean ahora más retadores. ¿Cómo se pueden ayudar y apoyar adecuadamente los programas para 185 niños que están en 138 escuelas diferentes en el estado? Estas 138 escuelas definitivamente requieren un nivel mayor de asistencia que en el pasado, ya que generalmente no emplean especialistas en sordoceguera. Con uno o dos niños por edificio, o frecuentemente por distrito, no es posible que puedan hacer el gasto de tener un especialista con tan bajo número de incidencia.

En la mayoría de los estados (estos) factores dan como resultado la repetición del entrenamiento, una y otra vez, a un nivel de estrategias instructivas muy elementales que son efectivos con los niños sordociegos sin tener en cuenta las diferencias individuales de los estudiantes. El resultado es que muy pocos de los educadores adquieren el conocimiento necesario para hacer un buen plan educativo para los niños.

Si hace dos décadas tuvimos escasez de personal, hoy en día ha aumentado diez veces. Solamente tres o cuatro universidades a nivel nacional reciben apoyo federal para programas de pre-servicio para entrenar a los maestros de niños sordociegos, y entrenan 20 maestros anualmente. Muchas otras Universidades ofrecen programas sobre incapacidades severas, pero hay gran variación en el alcance con el que ellos abordan los déficits sensoriales, y frecuentemente la sordoceguera recibe sólo atención superficial. Por favor, recuerden que esto está ocurriendo en una época en la que hay gran necesidad de maestros entrenados, debido a que los niños reciben servicios en un gran número de lugares. Los sistemas escolares locales, que tienen la obligación de educar al niño, tienen que hacerlo sin el personal con la experiencia para entrenar y apoyar a los maestros.

En la era actual los fondos son escasos y difíciles de conseguir. La sección federal, programa 622, actualmente destina $128 millones para servicios en toda la nación. Debido al costo de vida actual, con esta cantidad de dinero se pueden conseguir menos servicios de lo que se podía conseguir a principios de 1970 con $16 millones.

El Dr. Dávila, hace un buen resumen de nuestras deficiencias: "Esta filosofía, que se centra en la participación total de la persona que tiene alguna incapacidad en todos los aspectos de la vida comunitaria, hasta cierto punto ha superado nuestra habilidad actual para convertir la filosofía en una realidad para todos los que ella acoge... Aunque nosotros en OSERS acogemos el concepto de completa inclusión, también creemos que nuestra filosofía sobrepasa nuestra capacidad actual para lograrlo totalmente".

Asimismo, OSERS advierte a las escuelas que el ambiente menos restrictivo para un niño sordo no es precisamente el aula regular. Debido a que por la naturaleza de la sordera "inherentemente aislante" y por los problemas especiales que los niños sordos tienen para aprender el lenguaje, "no hay métodos efectivos de instrucción disponibles que puedan implementarse en una variedad de lugares educativos" dice OSERS. Dice también que "esta falta de conocimiento y habilidades en nuestro sistema educativo contribuye a las barreras existentes que tienen que enfrentar los estudiantes sordos para recibir servicios educativos apropiados... Cualquier ambiente, incluyendo un aula regular, que impide que un niño sordo reciba la educación apropiada para satisfacer sus necesidades, incluso las necesidades de comunicación, no es el ambiente menos restrictivo para ese niño en particular" (Registro Federal, 1992). Si esto es cierto para niños sordos, ¿porqué no se aplica esto mismo para el niño que tiene problemas del oído y de la visión?

Los niños sordociegos generalmente requieren cierto contenido educativo dentro de su IEP, para que su educación sea apropiada. Como todos los niños que tienen incapacidades graves, necesitan currículos funcionales, con actividades apropiadas a su edad, entrenamiento vocacional, interacción social con los compañeros. Sin embargo, un plan educativo para un niño sordociego debe contar por lo menos con:

* Metas de lenguaje en la forma más usada por el niño, y escritura al nivel actual del lenguaje del niño.

* Actividades sensoriales de desarrollo. Estas generalmente incluyen entrenamiento del oído siguiendo un sistema progresivo establecido, y en el caso de niños que pueden ver parcialmente, actividades de estimulación para poca visión que también sigan un sistema progresivo.

* Estrategias de enseñanza que tengan en cuenta el estilo de aprendizaje del niño, según las estrategias apropiadas de evaluación. Es importante saber con cuál coeficiente aprende mejor el niño, cómo enfrenta las distracciones del ambiente; dónde se pueden colocar los materiales para que el niño pueda ver; qué tan estructurado debe estar el ambiente y la enseñanza para que el niño tenga sentido de su mundo; ecológicamente, qué cosas en el ambiente del niño promueven vs. impiden el aprendizaje... y así sucesivamente.

* El entrenamiento para la movilidad para desarrollar la habilidad de la persona para explorar y convivir en su ambiente, hasta donde sea posible.

* Enfasis en ampliar las habilidades cognitivas del estudiante y para (adaptar) el currículo para reconocer que ellos no pueden observar este mundo muy bien. Estas adaptaciones pueden incluir (entre otras) más oportunidades de exploración con el tacto; mayor uso de modelos y objetos verdaderos para explicar los conceptos; más viajes y experiencias verdaderas en vez de la discusión en las aulas; más preparación en información descriptiva para preparar al estudiante que no puede ver el material instructivo, y más interpretación individual de los sucesos que ocurren en el aula y en todo el ambiente. El joven sordociego necesita instrucción específica en el uso de objetos y sus diversas funciones, gradualmente expandiendo el uso de objetos del niño mediante la instrucción incremental. Hay que enseñar de manera especial estos conceptos, debido a que el niño sordociego frecuentemente no puede observar cómo las otras personas hacen uso de los objetos (Enright, 1977).

* Evaluando las capacidades actuales del niño para la interacción social, y creando situaciones en las que se asegura la oportunidad para que tales interacciones puedan ocurrir. Frecuentemente el niño sordociego necesita que se le enseñe específicamente el comportamiento social, desde la aceptación de los demás en su vida, relacionarse con los demás a través del lenguaje, jugar con los demás, y respetar los turnos. Si el niño sordociego no observa las interacciones sociales de los demás, él no puede obtener un modelo de este tipo de comportamiento, y por lo tanto, frecuentemente necesita enseñanza específica para adquirir estas habilidades. Obviamente, para los estudiantes que ya tienen un sistema desarrollado del lenguaje, es importante que estas interacciones sociales ocurran en el lenguaje principal del niño para que esta interacción sea de "calidad" para que el estudiante sordociego pueda beneficiarse, y se pueda lograr el progreso en el desarrollo social.

* Sin considerar el nivel de funcionamiento, cualquier estudiante que pueda beneficiarse significativamente de la tecnología educativa actual disponible debe tener acceso a ésta, y debe tener instrucción apropiada para su uso. Esto es cierto si se trata de un *head-switcher* para un niño con severa parálisis cerebral, o de software para cambiar la palabra impresa a escritura en braille para un estudiante en un programa de inclusión.

Además de estos factores, para los estudiantes que tienen la capacidad académica, se puede considerar otro currículo, si es que un programa educativo se puede juzgar apropiado. En primer lugar, los estudiantes deben tener la oportunidad de aprender a leer y escribir. Los estudiantes con la capacidad para aprender tienen el derecho a ser educados, y nosotros tenemos la obligación de enseñarles. Si esta capacidad puede lograrse mediante la imprenta, o si el niño solamente puede aprender a leer mediante el braille, si ellos pueden aprender, ellos deben de aprender. Asimismo, si el estudiante es capaz de seguir una sucesión "normal" razonable de cursos, y obtiene un diploma de preparatoria, ellos deben tener esta oportunidad. Es injusto dar un "certificado especial" a los estudiantes que tienen capacidad para obtener un diploma, solamente porque nosotros no sabemos adaptar el currículo para ellos.

Pienso que, muchas veces, el contenido específico que necesita el niño, debido a su sordoceguera, es deficiente.

Esto sucede en los programas de inclusión así como en algunas de las clases aisladas para niños con graves incapacidades, donde hay niños sordociegos. A veces un maestro de niños que tienen limitaciones del oído o de la visión, o una persona con conocimiento de las necesidades especiales moderadas o severas, asesora la clase regularmente. Sin embargo, muchas veces, esta no es una persona con verdadera experiencia para evaluar las necesidades del niño y ofrecer un currículo que incorpore los factores que se mencionan arriba. El resultado es que el niño recibe un programa apropiado sólo en parte. Algunas de las necesidades se mencionan en el IEP, y otras no se mencionan, de acuerdo con la experiencia de la gente que está a la mano.

A veces, no sólo el distrito carece de esta experiencia, sino también no hay nadie a quien se le pueda llamar en el condado en el sistema intermedio escolar o en el estado. Por lo tanto, lo que se obtiene solamente incluye una parte de las necesidades del niño. Una carencia comprable de conocimiento por parte del personal de recursos del estado producirá los mismos problemas en el plan del estudiante.

Esta situación no es aceptable. Nosotros no podemos seguir creyendo que un sistema con tan grandes problemas pueda ser un sistema funcional. Nosotros nunca podremos mejorar la calidad de lo que reciben los niños sordociegos a nivel local a menos que todos nos demos cuenta que se necesitan mejoras importantes. Esto se debe reconocer a cada nivel, desde el Departamento de Educación de U.S. hasta el asistente de maestro contratado más recientemente y que se ha asignado a un niño sordociego por primera vez. Para arreglar el problema, nosotros debemos primero reconocer el problema.

UN FUTURO MEJOR
PASOS DE ACCION PARA OSERS

Muchos de los problemas que tenemos ahora en la educación para los sordociegos han evolucionado debido a un cambio rápido en la descentralización de los consumidores. Las personas que trabajan directamente con la gente y no solamente los que están empleados en las universidades o que tratan de obtener concesiones. No entiendo por qué un programa nacional diseñado para beneficiar a una población específica no tiene un comité asesor compuesto por consumidores y profesionales en el campo.

PASOS DE ACCION PARA NOSOTROS MISMOS

Además de alterar los medios prácticos por los cuales se dan los servicios y se entrena al personal también debemos cambiar nuestra orientación filosófica. Hay varias cosas que debemos reconocer en nosotros mismos si vamos a mejorar, en vez de repetir los mismos errores.

1. Primero, quiero recordarles que la filosofía educativa actual dentro de nuestro campo está muy lejos de ser un servicio especializado y tiende a ofrecer servicios generales. Nosotros debemos seguir firmes en nuestro plan de rehusar el aceptar el sabor a vainilla para una población cuyas necesidades requieren los 28 sabores. Un respaldo de servicios generales es un respaldo a las insuficiencias actuales en nuestro sistema, y el silencio es siempre un respaldo.

2. Nosotros los que estamos en la educación especial nos conformamos con la "voluntad de la mayoría." Simplemente analice las palabras de moda de las últimas dos décadas: el análisis de la tarea, la modificación del comportamiento, la formación modelo, terapia sensitiva de integración, el movimiento coactivo, la estimulación vestibular, el ambiente menos restrictivo apropiado a la edad, inclusión, ecológica, el tratamiento no aversivo, la integración, la comunicación facilitada y la inclusión completa. Nuestra tendencia es seguir lo que está de moda y actuar como si todo lo que nosotros aprendimos anteriormente está ahora obsoleto e irrelevante. Así no se acumulan el conocimiento científico ni tampoco una buena filosofía educativa.

3. Nosotros debemos buscar fortaleza en nuestras convicciones, para abogar por lo que es bueno para los niños y adultos sordociegos. Anteriormente, cuando predominaban las filosofías educativas o cuando las prioridades administrativas tenían resultados negativos para nuestras poblaciones, nosotros no nos hemos quejado. Nosotros no debemos dudar en enseñar los problemas de los servicios. Nosotros debemos ayudar cuando sabemos qué se necesita, y admitir cuando no sabemos. Debemos insistir sobre el nivel de especialización que esta población requiere, porque nadie más lo va a hacer. Debemos servir como defensores de la población, y estar dispuestos a ir a las audiencias o a la corte para defender las necesidades de las personas sordociegas.

4. Nosotros debemos comenzar a concentrarnos más en la calidad del contenido programático e instructivo que reciben los sordociegos, y pensar menos en el lugar donde la persona recibe los servicios. La calidad de los servicios se determina por medio de muchos indicadores, uno de los cuales es el número de compañeros no incapacitados en el ambiente.

5. Permítanme hacer un paréntesis para recordar las palabras de F. Scott Fitzgerald: "La prueba de una inteligencia de primera es la capacidad para retener dos ideas opuestas en la mente a la vez y todavía mantener la capacidad para funcionar". NOSOTROS debemos comenzar a imponer nuestros valores sobre los beneficios de la integración y los beneficios del conocimiento experto. Nosotros hemos actuado como si estas dos ideas fueran completamente opuestas, cuando de hecho la especialización debería funcionar bastante bien en todos los lugares. Nosotros hemos argumentado excesivamente sobre dónde se debe atender a los niños y no nos hemos preocupado lo suficiente sobre lo que deben recibir.

Recordando las palabras de Lori Goetz, "Tú sabes que todo este énfasis en la integración y la inclusión ha sido muy bueno, y es muy importante... y nosotros debemos seguir haciéndolo... sin embargo, estos niños necesitan más que buenas amistades e interacciones sociales con compañeros que no tienen incapacidades... nosotros olvidamos que ellos tienen que aprender algo... nosotros de algún modo tenemos que enfocarnos otra vez para asegurar que cada niño aprenda también, y tenga un contenido educativo apropiado". Continuó diciendo, que varios de los programas de inclusión con los que ella trabaja tienen considerable dificultad al ofrecer un contenido instructivo apropiado. Ella resumió en estas pocas palabras las ideas que estoy presentando hoy.

Esta época de cambio en los servicios ha sido turbulenta, lo que ha hecho que todos nos sintamos por lo menos un poco inseguros de nuestros valores y prioridades de los servicios para las poblaciones sordociegas. Usando las palabras del Dr. Dávila nuevamente,..."yo veo el tiempo en el que vamos a mirar hacia la década de los 90, nuestras frustraciones, nuestro crecimiento, nuestro cambio, nuestros éxitos y fracasos, y nosotros veremos esos pasos como parte de un proceso largo, frecuentemente doloroso, pero finalmente un proceso útil" (Dávila, 1990). Yo espero que a lo largo de nuestros propios cambios y evoluciones también miremos hacia estos días de cambio y nos sintamos orgullosos de que nosotros insistimos en una norma educativa de calidad para los niños sordociegos.

Puntos sobre la evaluación de la pérdida de la vista con respecto al lenguaje de señas y deletreando con los dedos para el estudiantesordociego

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NECESIDADES DE LOS NIÑOS SORDOCIEGOS

Cuando un niño es sordo o no puede oír bien, su acceso a la información y la interacción se basa principalmente en su vista. Debido a que el lenguaje de señas y el deletreo con los dedos son intensamente visuales por naturaleza, la pérdida de la vista afecta la capacidad del niño para tener acceso y adquirir estas formas de comunicación. Por esta razón, es importante identificar cualquier pérdida de la visión que pueda afectar la capacidad del estudiante para tener acceso a la información educativa.

Se debe evaluar el efecto de la pérdida de la vista del estudiante con respecto al acceso y uso de formas de comunicación visual para que se puedan poner en práctica las adaptaciones apropiadas. Evaluación de la comunicación, Evaluación Funcional de la Visión, o Evaluación del Aprendizaje a través de los Medios de Comunicación (LMA) muchas veces no tocan este punto. Puesto que este punto es tan complejo, la evaluación de la visión debe planearse y efectuarse cuidadosamente.

Trabajando con educadores en Texas, hemos desarrollado un método para evaluar el efecto de la pérdida de la vista en la capacidad del niño para tener acceso a la información y aprender mediante estas formas de comunicación. Quise compartir esta información, esperando que pueda ser útil para aquellos que estén enfrentando la misma tarea.

PREPARACION PARA LA EVALUACION

Forme el equipo de evaluación

Para obtener la información necesaria se requiere el trabajo en equipo. El proceso de evaluación requiere de alguien que pueda comprender lo que el niño está diciendo con señas, lo que se le está diciendo al niño con señas y qué obstáculos visuales específicos deben ser superados para que el niño pueda aprender y use estas formas de comunicación. Específicamente, el equipo necesita incluir a un maestro de personas con limitaciones visuales y un maestro para los sordos o con dificultades para oír. Estos dos maestros tienen información especial que el otro no tiene, lo que requiere que los dos colaboren entre sí.

El equipo puede necesitar también apoyo de un profesional con experiencia en sordoceguera. El entrenamiento específico sobre la evaluación y el desarrollo de programas para estudiantes con sordoceguera no está incluido en los programas de adiestramiento para maestros de las personas con limitaciones visuales o profesores para los sordos o con dificultades para oír. Esta información es especial en el campo de los sordociegos. Además, el intérprete del aula está entrenado para proveer servicios a la persona sorda o que tiene dificultades para oír, pero puede que no esté familiarizado con adaptaciones que necesita el niño sordociego para tener acceso a estas formas de comunicación.

Haga evaluaciones estándar

El proceso para evaluar los efectos de la pérdida de la vista y reconocer y usar formas visuales de comunicación está unido a la Evaluación Funcional de la Visión y a la Evaluación del Aprendizaje a través de los Medios de Comunicación (LMA). Llevar a cabo estas evaluaciones es responsabilidad principal del maestro de la persona con limitaciones visuales en colaboración con el resto del equipo. En equipo debe determinar cómo reunir esta información. El maestro de personas con limitaciones visuales puede informar a Evaluación Funcional de la Visión o LMA sobre el impacto de la pérdida de la vista del estudiante, sobre cómo usa el lenguaje de señas y de deletreo con los dedos.

Reuna información

Después de que se completa la Evaluación Funcional de la Visión, el equipo necesita reunir alguna información específica.

1) *¿Cuál es la causa de la limitación del niño?*
Hay un número de síndromes que tienen como consecuencia la pérdida de la vista y del oído. Esto puede tener efecto en el enfoque educativo que se debe usar con el niño o guiar el tratamiento médico que se debe seguir a largo plazo. Por ejemplo, el Síndrome de Usher trae pérdida de los campos visuales. Los niños con el síndrome de rubéola congénita tienen el riesgo de cataratas y glaucoma. Los recursos como la *National Organization for Rare Diseases* (NORD) y *D-B Link* pueden ser muy útiles para obtener esta importante información. Hay otras causas de la pérdida de la vista. Por ejemplo la meningitis espinal puede asociarse con *cortical visual impairment* = limitación de la visión cortical, y da como resultado una visión variable y posibles problemas de percepción.

2) *¿Qué sistema o metodología de comunicación se está usando con el niño?*
Hay varios sistemas o metodologías de comunicación manuales que se están usando en las aulas de Texas en este momento. Una frase o pensamiento se puede expresar de varias maneras, dependiendo de qué sistema o metodología de comunicación se usa, dando como resultado diferentes exigencias de parte del niño. **La figura 1** da algunas definiciones muy simples de estas metodologías o sistemas. (La figura 1 no es completa y sólo se usa para introducir estos términos. No se debe usar ninguna de estas metodologías o sistemas para respaldar ni criticar).

FIGURA 1-Manual de comunicación
Sistemas y metodologías

Lenguaje Americano de Señas (ASL): "la lengua natal de miles de personas sordas que tienen padres Sordos. Para ellos, es no solamente su primer lenguaje sino que también conlleva la cultura de generaciones de personas sordas en América. Al igual que otras lenguas extranjeras, tiene su propia historia, expresiones idiomáticas, estructura y reglas gramaticales". Es un lenguaje visual altamente sofisticado y no está basado en el inglés ni tampoco se derivó del inglés. (Humphries, et al. 1980).

Lenguaje de Señas en Inglés (S.E.E. signs): Sistema de señas que se desarrolló en los primeros años de la década de los 70 basado en el idioma inglés. "El principio más importante en Lenguaje de Señas en Inglés es que se deben hacer señas en un inglés uniforme a la manera como se habla o escribe..." (Gustason, et al. 1993).

Deletreo con los dedos: Las letras individuales del alfabeto se producen manualmente con la mano dominante mediante formas específicas. En este país, nosotros normalmente usamos el *American One Hand Manual Alphabet* = Alfabeto Manual American de una Mano. Se puede usar en combinación con el lenguaje de señas.

Comunicación total (TC): El inglés se habla y se comunica con señas usando simultáneamente la gramática y la sintaxis del inglés.

Observe al niño

Hay pruebas diseñadas para verificar el vocabulario receptivo de señas. Sin embargo, estas pruebas normalmente dan el estudiante la ventaja de ver una por una las señas, desde una distancia uniforme y con un número limitado de respuestas. Los resultados pueden indicar claramente las señas precisas que el niño sabe en un ambiente clínico, pero no ayudan a saber su capacidad para reconocer las señas en otros ambientes o situaciones. La pérdida de la vista le pueden impedir su comprensión "funcional" de estas formas comunicativas.

Por lo tanto, usted debe observar al niño en estas situaciones y ambientes reales. Normalmente, nosotros hemos tomado las preguntas que encontrará más adelante y hemos dejado que esas preguntas guíen nuestras observaciones del niño en una variedad de interacciones a lo largo de su día normal. Estas observaciones se efectúan durante el curso de varios días de modo que nosotros podamos obtener una amplia muestra del funcionamiento del niño.

Una nota para tener en cuenta sobre lo que usted observa: Es posible sobreestimar las habilidades de comunicación receptivas del niño. Por ejemplo, el estudiante puede reconocer a alguien que está haciendo señas sin realmente distinguir segmentos discretos de la seña o señas. Por ejemplo, el maestro muestra en alto un folder amarillo de arte y señala "Hora de arte". A veinte pies de retirado, él puede ver el folder de arte, notar que el maestro está haciendo señas y adivina que le están diciendo que debe ir a arte. Eso no significa que este niño pueda distinguir todas las señas a veinte pies de distancia.

El método de adivinar funciona mejor en cosas rutinarias, usted puede observar una reducción importante en la comprensión del niño con el lenguaje de señas en ambientes y situaciones nuevas. El puede necesitar distancia o instrucciones diferentes cuando se le presenta nueva información.

PREGUNTAS DE LA EVALUACION Y POSIBLES ADAPTACIONES

A continuación está la lista de preguntas que orientan las observaciones. Hay algunas consideraciones y posibles modificaciones, adaptaciones, o estrategias de enseñanza. Esta lista no es completa. Puede haber otras preguntas que su equipo quiera hacer. Las adaptaciones que ustedes seleccionen son altamente individualizadas y deben ser según la visión del niño y sus preferencias para hacer señas.

1) *¿Cuál es el mejor espacio, lugar y distancia para hacer señas/deletrear con los dedos, respecto a los campos de visión del niño?*

Por regla general, la comunicación manual se hace dentro de un área cúbica de dos pies. Los estudiantes con pérdida de visión (puntos ciegos) en su visión pueden tener mucha dificultad para ver las señas dependiendo del lugar y tamaño de la pérdida del campo de visión. El no ver partes del mensaje puede afectar mucho la comprensión. Es importante saber cuál es la mejor área para que el niño pueda ver la comunicación manual. Para hacer esta determinación, usted necesitará saber el mejor lugar (por ejemplo, cuadrante central, superior, izquierdo, o derecho) y espacio para reconocer las señas (por ejemplo, un radio de 10 pulgadas). Si el estudiante tiene una pérdida del campo de visión, el moverse más retirado de la persona que hace señas, le permite ver más de su cuerpo y ve más de la información. Cuando un niño tiene un problema de agudeza visual (visión borrosa) y una pérdida del campo de visión, es más complicado encontrar la mejor distancia.

En sus observaciones, tome nota del estudiante que constantemente retrocede cuando usted trata de hacer señas. El puede estar tratando de verlo mejor a usted en su campo de visión limitada. También tenga en cuenta a los estudiantes que tocan su muñeca o la mano, estiran la mano y vuelven a colocarla, mueven la cabeza hacia atrás o usan excéntricas posiciones para ver (por ejemplo, siempre bajan la cabeza y la mueven a la izquierda para usar su visión periférica). Los profesores pueden informar que tienen problema para retener la atención del niño desde un lado en particular. Trate de hacer señas desde diferentes lugares y a diferentes distancias sistemáticamente dentro de un cuadrante. Compare estas observaciones con la información obtenida en la Evaluación Funcional de la Visión. ¿Estas observaciones confirman cuál es la mejor área de visión del niño?

Adaptaciones que se pueden hacer:
* Reducir el espacio al hacer señas. (por ejemplo, la seña de "país" se puede hacer entre la muñeca y el codo en vez del codo). Esto puede ayudar a los estudiantes con pérdida del campo de visión porque mueve la seña en su campo visual.
* Deletrear con los dedos algunas palabras (en vez de señas) si el movimiento de la seña se hace fuera del campo de visión del niño (por ejemplo, se hacen señas para comunicar "Rusia" colocando las manos sobre las caderas).
* Sustituir una seña que requiere un espacio menor para hacer señas, mientras que el significado no cambie.
* Alterar la distancia para hacer señas (con base en el tipo de pérdida de campo de visión) entre usted y la persona sordociega.
* Si un maestro o un intérprete tiene otros estudiantes que también hacen señas, otra persona que ayude puede ser la mejor modificación para el estudiante con sordoceguera. El presentar las señas constantemente en el mismo campo de visión, a la misma distancia y dentro de un área precisa, o continuamente usando señas modificadas puede ser difícil si no imposible en un aula donde se comunica por medio de señas.
* Considerar el uso de aparatos que ayuden a aumentar la cantidad de información que el niño con poca visión recibe (por ejemplo, telescopios de campo expandidos).
* Permitir al niño voltear su cabeza para usar posiciones excéntricas si es necesario.
* Usar el tacto en algunas situaciones.

2) *¿Cuál es la mejor distancia y rapidez para hacer señas y deletrear con los dedos, que permita al niño leer más eficientemente en diferentes situaciones de instrucción o situaciones de conversación?*
La distancia apropiada para hacer señas y deletrear con los dedos puede variar según la complejidad del cambio, la cantidad de apoyo contextual que ayuda a adivinar, y las características de la seña o letra individual. Algunas señas son muy concretas y tienen movimientos claros y grandes (por ejemplo, "cepillar dientes"). Otras señas son más abstractas y tienen señas más sutiles, movimientos menos claros (por ejemplo, "siete"). Las señas también pueden parecerse (por ejemplo, "morado" y "verde"). Cuando se deletrea con los dedos, la mano se queda en un lugar eliminando los tipos de claves que proveen muchas palabras expresadas con señas. Por ejemplo, "rey" es distinto debido al movimiento del hombro a la cadera. También, algunas letras que se hacen con la mano son muy similares para las personas con pérdida de agudeza visual (por ejemplo, a, t, n, m, o, s, e). La rapidez normal para deletrear con los dedos es de 3-4 letras por segundo y esto puede presentar un problema para el niño que tiene una limitación visual.

También se debe considerar la distancia entre el compañero que hace las señas. Si el estudiante tiene problemas de agudeza, él tendrá que estar suficientemente cerca a su compañero para enfocar las manos, la cara y el torso de la persona. La distancia y rapidez apropiadas para hacer señas o deletrear con los dedos se basa en la habilidad de comprensión del niño y puede variar según el lugar.

Cuando usted combina señas y palabras deletreadas con los dedos, puede que necesite hacer señas más lenta y claramente. Esto es muy difícil cuando hay que incluir a otros estudiantes. Sin embargo, usted tiene que usar la rapidez que es más apropiada para el niño con limitaciones de la visión.

Adaptaciones que se pueden hacer:
* Variar la rapidez de las señas y deletreo con los dedos de acuerdo a la situación cuando la información es compleja o nueva.
* Trabajar individualmente con el niño para mejorar su

comprensión de señas y deletreo con los dedos mediante las prácticas receptivas.
* Determinar la mejor distancia receptiva en estas situaciones.
* Usar señas o deletreo táctiles cuando sea necesario (ver preguntas sobre señas táctiles).
* Considerar el uso de aparatos que ayuden con la baja visión para aumentar la cantidad de información que el niño recibe (por ejemplo, un aparato monocular de distancia).
* Considerar el uso de personal adicional si la distancia y rapidez varían significativamente del que requieren los otros estudiantes en la clase.

3) *¿Los estudiantes pueden distinguir con la visión los movimientos que dan significado a las señas?*
En ASL se usa una combinación compleja de señas manuales y no manuales. Estas señas deben verse al mismo tiempo porque la seña que no es manual cambia el significado de la seña manual. Unos pocos ejemplos de señas no manuales son: labios fruncidos, mejillas sopladas, una ceja levantada. Cuando las señas específicas se combinan con las señas manuales en una palabra, el significado de la palabra cambia. (Baker & Cokely, 1980). El niño quizás puede ver los grandes movimientos.de la mano, pero no puede ver el movimiento más sutil de la ceja. Por lo tanto, él no entiende lo comunicado.

Observe la comprensión de la información total por parte del niño. También tenga en cuenta la habilidad del niño para entender el temperamento de las personas o intentos de comunicarse con señas del cuerpo. Trate algunos juegos de imitación que requieren que el niño sea capaz de poner atención a los movimientos de la cara y de la mano o movimientos faciales o movimientos del cuerpo a la vez. ¿Pueden ellos ver ambos movimientos en una variedad de distancias?

Adaptaciones que se pueden hacer:
* Dar esta información de otra manera. Por ejemplo, en vez de hacerlo con expresiones faciales use más señas manuales para trasmitir la emoción (por ejemplo, haga la seña de "sospechoso" y a la vez expréselo con los ojos).
* Enseñe que los sentimientos se expresan usando señas con el cuerpo. El niño con una limitación visual puede no estar consciente de esto.

4) *¿La iluminación afecta la capacidad visual de acceso a la información por parte del estudiante?*
Para algunos niños, la iluminación escasa o muy brillante puede presentar retos. Como lo dijo un amigo que tiene limitaciones visuales, "La luz puede ser mi mejor amigo o mi peor enemigo".

Observe la habilidad del niño para comprender y responder a la comunicación manual en condiciones diferentes de iluminación. Observe si hay cambios en las habilidades cuando está adentro y afuera, bajo luz fluorescente y luz incandescente, en áreas con sombras o con poca luz, etc. Esté atento a las reacciones en el crepúsculo o en la noche.

Adaptaciones que se pueden hacer:
* Usar señas táctiles. Por ejemplo, cuando las luces se bajan para ver un video, un niño con la pérdida periférica puede necesitar este apoyo.
* Usar iluminación del área. Lámparas o luces direccionales sobre la persona que se está comunicando puede ser muy útil. Coloque la luz de modo que no dé sombra a las manos ni a la cara de la persona que está haciendo señas.
* Usar viseras, sombreros y lentes de sol para reducir el reflejo. Para los estudiantes con el Síndrome de Usher u otros padecimientos visuales, el reflejo es un obstáculo muy grande.
* La persona que hace señas no debe pararse dando la espalda a la luz (por ejemplo, pararse en frente de una ventana).
* La información por medio de transparencias se debe presentar de otra manera.

5) *¿Afecta el fondo visual la comprensión del niño?*
Los intérpretes profesionales visten trajes de colores sólidos obscuros cuando están interpretando para que den contraste a sus manos. Esto hace sus señas más claras y más fáciles de leer.

El niño con limitaciones visuales tiene que trabajar más duro para entender la información cuando el fondo visual es más complicado. Observe si las habilidades de comprensión del niño aumentan o disminuyen cuando se leen señas contra diferentes fondos visuales.

Adaptaciones que se pueden hacer:
* Vestirse de colores sólidos obscuros puede ayudar para que las señas sean más fáciles de distinguir. Si el maestro no tiene mucha ropa de un sólo color, obscura, entonces puede considerar usar un traje de un sólo color, obscuro.

* Seleccione el mejor color para mejorar el contraste del fondo. (por ejemplo, algunos niños pueden ver mejor con el color morado en el fondo en vez del color negro).

6) *¿Tiene el estudiante habilidades que motiven el cambio que necesita?*
Muchos niños, aun a muy corta edad, le dirán cuando no pueden ver lo que usted le está diciendo por medio de señas. Ellos se pueden alejar de sus tareas o no querer ver. Un niño más grande quizás mueva las manos para que estén dentro de su vista o puede criticar la forma en que usted hace señas. Tenga en cuenta si el niño puede evaluar su capacidad para ver en cualquier situación determinada y qué tan bien puede comunicar su dificultad visual a los demás. Finalmente, sólo la persona sordociega sabe lo que realmente le puede ayudar para entender la comunicación y él debe ser capaz de decir lo que necesita.

Adaptaciones que se pueden hacer:
* Trabajar individualmente con el niño para enseñarle a que le diga qué ajustes necesita.

7) *¿Puede un estudiante seguir una conversación a través de señas en un grupo?*
La instrucción en grupo requiere diferentes cosas que cuando se encuentra en situaciones de persona a persona. En una lección de grupo el maestro puede comenzar diciendo una frase por medio de señas, directamente al estudiante a una distancia de 6" a 12" pulgadas y después se puede voltear a otro niño para terminar la frase. Repentinamente las manos del maestro se han movido a una distancia de 30" pulgadas. Cuando esto ocurre, el estudiante con pérdida de la vista deja de ver las señas simplemente porque se movió fuera de su distancia visual.

La distancia y el ángulo de la comunicación manual cambia continuamente a medida que diferentes miembros del grupo participan en la discusión. El estudiante constantemente tiene que ubicar a la persona que está haciendo señas y enfocar otra vez a los que están haciendo señas. Quizás necesite cambiar de posición para ver las señas.

Tomar el tiempo adicional para adaptarse a las necesidades del niño sordociego frecuentemente rompe la continuidad de la lección en grupo. Usted puede saber si el niño necesita más tiempo para ver unos cuadros, si necesita que la personas le hagan señas más lentamente, o si tiene problema para seguir el movimiento de las manos. Sin embargo, el hacer estos cambios con constancia, mientras se hace la instrucción en grupo, puede ser imposible. Como resultado, es fácil ofrecer un nivel inferior de instrucción al niño sordociego.

Adaptaciones que se pueden hacer:
* Si el niño se incluye en actividades de grupo, puede necesitarse personal adicional para que le ayude.
* Señale con el dedo a la persona que va a hacer señas, y déle tiempo al niño para que la ubique visualmente.

Entrevistas

Después de que su equipo ha observado al niño en el ambiente educativo, comparta sus observaciones. Procure entrevistar a los miembros de su equipo que tienen la mayor experiencia con el niño en interacciones comunicativas. Debe incluir personas de la familia, al intérprete educativo, al asistente instructivo, etc.

No se olvide de hablar con el estudiante. En muchos casos él puede ser la mejor persona para decirle al equipo qué problemas tiene. Sin embargo, es importante recordar que unos niños no se dan cuenta que les falta información en ciertas situaciones.

Una vez que haya formulado una teoría sobre cómo usa el niño su visión, usted puede idear situaciones para llevar la teoría a la práctica. Los resultados pueden sugerir las adaptaciones específicas que quiere tratar. Puede ser que estas adaptaciones sean muy individualizadas no solamente de un niño a otro, sino también de situación en situación para cada niño. Esto ocurre porque una persona puede ser afectada por diferentes condiciones de luz, el grado de familiaridad con una situación, el número de exigencias visuales, etc. Si el niño tiene una pérdida progresiva de la vista o que varía, entonces las adaptaciones que se requieren puede cambiar en un período de tiempo corto o largo.

PREGUNTAS ADICIONALES

Después de contestar el primer grupo de preguntas, haciendo entrevistas al personal y a la familia, y sacando algunas conclusiones sobre el funcionamiento visual del niño, con frecuencia encontramos que necesitamos preguntar cosas adicionales.

8) *¿Se beneficiará el estudiante con la experiencia de trabajo complementario para ayudarle a entender los conceptos que van más allá de las señas?*
Los niños que son sordos o que no pueden oír bien tienen una riqueza de información visual incidental que les sirve como base para el lenguaje. Este quizás no sea el caso para un niño con sordoceguera. Gran cantidad de esta información especial se deforma o se pierde completamente para un niño que sufre pérdida de la vista junto con la pérdida del oído. Por ejemplo, este niño nunca podrá ver un pájaro volando o parado en un árbol, ni ver un pájaro. El mostrarle un cuadro o hacerle las señas para indicar un pájaro asume que sabe no solamente la seña que representa, sino el concepto de lo que es un "pájaro". Pero esto quizás no es cierto para él.

La información nueva no debe presentarse en forma de cuadro o seña si el niño no tiene una experiencia firme para asociar el cuadro o la seña. Aun cuando él puede tener la habilidad de entender o recordar la información, si no está obteniendo toda la información en primer lugar, es virtualmente imposible que lo entienda. Este es un punto de acceso. Los niños sordociegos necesitan mayor número de experiencias, organizadas con objetos y acciones reales antes de poder entender verdaderamente los cuadros, el deletreo con los dedos, o señas que representan estos objetos y acciones. Su pérdida sensorial no les permite estas experiencias.

Aunque el niño tenga una buena base de experiencia puede necesitar complementar el trabajo de experiencia. Las demostraciones y modelos se usan ampliamente con estudiantes sordos o que no pueden oír bien. Si el estudiante no puede ver la demostración, él necesita hacer la acción por sí mismo. Para los estudiantes con restricciones en el campo visual, que pueden ver la demostración, observar demostraciones mientras se dan la señas simultáneamente requiere de rápidos cambios de observación. Parte de la información se puede perder en el proceso. Los objetos necesitan ser examinados con el tacto y con la vista antes de que se puedan reconocer cuando se ven a distancia. El niño con pérdida de agudeza visual puede perder información o también puede recibir información distorsionada. También la clase de demostraciones puede ser muy difícil para él.

Adaptaciones que se pueden hacer:
* Proveer experiencia complementaria para construir una base global del concepto.
* Permitir que el niño vea la demostración individualmente antes de que participe en la demostración con el grupo.

9) *¿Es la visión del niño tal que puede beneficiarse de la técnica de hacer señas coactivamente cuando aprende señas nuevas?*
El hacer señas coactivas es una técnica que enseña a hacer señas expresivas a los estudiantes con limitaciones visuales y que no pueden ver el modelo del instructor. Cuando se enseña a hacer una seña, el instructor toma la mano del estudiante y le ayuda al estudiante a formar la seña correctamente. Esta técnica puede también usarse con estudiantes que tienen problemas de percepción visual porque estos niños no son capaces de aprender las señas simplemente viendo a los demás. Mientras que las señas coactivas enseñan al niño a hacer señas, él todavía tiene que aprender a leer las señas cuando los otros las producen. Por lo tanto, es importante dar al niño oportunidad de verlo a usted hacer la seña (o leer con el tacto) si van a aprender a entender la seña recíprocamente.

El SKI*HI Institute ha producido 12 videos que ayudan a los familiares y a los profesionales a usar efectivamente las señas coactivas (Watkins, 1991).

10) *¿Inicia el niño el seguimiento táctil o se beneficia con él?*
El seguimiento táctil se usa cuando la persona sordociega coloca las manos en el área de las muñecas de la persona que está haciendo las señas. Esta técnica permite a la persona con limitaciones visuales saber dónde se están moviendo las manos del que hace las señas para poder dirigir su mirada correctamente. El también puede recibir suficiente información del lugar general de la mano para reconocer la seña sin verla claramente. El seguimiento táctil también se puede usar junto con otras adaptaciones mencionadas en la pregunta #1.

Algunos niños inician esta técnica ellos solos. Este es un indicio de que ellos necesitan más información de la que están recibiendo visualmente. A veces esto puede indicar una pérdida del campo de visión. El seguimiento táctil debe estar en la lista de estrategias del niño ya que hay algunas situaciones cuando la estrategia de alejarse de la persona que está hablando no es práctica (por ejemplo sentarse junto a un amigo en el autobús cuando la distancia para ver es mejor desde los 4 pies). A este niño debe permitírsele que se cambie al uso de seguimiento táctil cuando quiera. Algunas veces, hay que enseñar esta técnica al niño.

11) *¿Inicia el niño las señas táctiles o se beneficia con ellas?*

Nota: Esta es una discusión abreviada de los puntos importantes de las señas táctiles. Hacer señas táctiles, es una habilidad receptiva, no debe confundirse con las señas coactivas que se usan con las señas expresivas.

Las señas táctiles se usan con personas que entienden las señas del lenguaje pero que no pueden leer visualmente las señas y el deletreo con los dedos. Para recibir la información, "la persona sordociega pone una mano o las dos en las manos del que está haciendo señas para poder leer las señas y el deletreo con los dedos por medio del sentido del tacto. (Si es)... una adaptación directa al sentido del tacto de un sistema de comunicación que originalmente se hizo para la visión"... (Reed, et al. 1995). El usar las señas táctiles es una habilidad receptiva.

Las señas táctiles se usan normalmente con los estudiantes que son ciegos. Para los estudiantes que aprenden señas visuales y luego sufren significativas pérdidas de la vista, hay un proceso para volver a aprender las señas con el tacto. Las señas se sienten diferentes a como se ven. También puede haber puntos emocionales qué enfrentar para poder cambiar a las señas táctiles porque es admitir que no pueden ver. Este es un cambio muy difícil para las personas que no pueden oír bien o que son sordas.

Para poder ser un buen lector de señas táctiles una persona tiene que aprender cómo se sienten las señas. Tiene que aprender cómo poner las manos para poder obtener mejor información sin interferir con la persona que habla a señas. Generalmente, el estudiante usa ambas manos al principio. A medida que sus habilidades aumentan o si él está muy familiarizado con su compañero, puede usar sólo una mano. El estudiante va a necesitar "mantener el peso liviano" esto significa cuánto peso pone en las manos de la persona que está haciendo las señas. El compañero se puede fatigar rápidamente, y a través del tiempo, pueden ocurrir daños como el Síndrome del Túnel Carpiano si no se toman descansos adecuados. La persona sordociega también se puede fatigar porque el detener las manos en un solo lugar por largo rato produce cansancio, y el leer señas táctiles requiere gran concentración.

Mucha de la información que se trasmite en el lenguaje de señas se expresa mediante expresiones faciales, mirando a los ojos, movimientos leves, etc. Con las señas táctiles, debe hacerse cada intento para encontrar formas alternativas de comunicar el significado con el tacto.

Cuando se conversa con alguien o se está interpretando para una persona sordociega, hay que dar información adicional del lugar a lo largo de la conversación o la conferencia. Por ejemplo, hay que dar información sobre quién hay en el salón, una descripción de los muebles, un ruido, etc. Sin esta información algunos de los comentarios no pueden tener sentido si las personas se están refiriendo a las cosas que la persona sordociega no puede ver u oír. Pida a cada persona que diga su nombre antes de hacer comentarios y dé al intérprete una lista de dónde están sentados que contenga los nombre de los que están en el grupo.

Las señas táctiles las usan las personas que tienen pérdida total de la vista, y por las personas que pueden ver pero que no pueden ver las señas y el deletreo con los dedos suficientemente claro para poderlos entender. Si un estudiante que tiene poca vista inicia esta modificación, debe de ser respetado como un intento para obtener más información. El niño debe tener la oportunidad de recibir señas táctiles. Algunos estudiantes necesitan usar señas táctiles en algunas situaciones y no en otras. Por ejemplo, un estudiante puede necesitar depender de señas táctiles porque no hay suficiente luz, pero puede funcionar sin usar el tacto cuando hay buenas condiciones de iluminación.

En algunas ocasiones, el usar las señas táctiles puede permitir al niño seguir una discusión con sus manos mientras él usa su visión para observar el artículo que se está discutiendo. El no tiene que seleccionar lo que tiene que ver. Cuando un niño aprende más las señas, al leer frases más largas, quizás no puede depender solamente de su vista. El puede cambiar de las señas táctiles porque puede cambiar el nivel de la exigencia de su visión. Para otros estudiantes, el iniciar las señas táctiles puede significar que tienen problemas con la visión.

El usar las señas táctiles puede afectar la forma y rapidez en que se da la lección. Por ejemplo, si hay materiales que se usan junto con la lección, el niño tiene que tener tiempo de examinar los materiales antes de que pueda regresar las manos a su compañero. Si un maestro está haciendo señas a otros estudiantes, es difícil detenerse y repetirle al estudiante sordociego con señas táctiles todo lo que había dicho. El maestro también debe trasmitir cualquier comentario que los otros estudiantes hicieron al igual que leer la información del pizarrón y del proyector. Casi sin excepción se necesita un miembro adicional que dé la ayuda táctil.

12) *¿Si un estudiante se puede beneficiar con braille, hay cuestiones de comprensión del inglés con los estudiantes sordos o que no oyen bien, que se deban tener en cuenta?*

Cuando se determina si se debe usar información impresa o braille para un estudiante que es sordo o no puede oír bien, los profesores necesitan tener en cuenta que la lentitud al leer y los problemas con la comprensión pueden deberse a la dificultad para aprender el idioma inglés. En muchas formas, las necesidades de aprendizaje de estos estudiantes son las mismas que para los que aprenden el inglés como segunda lengua. El cambio en el medio de aprendizaje de la información impresa al braille quizás no mejore la lectura para los estudiantes que tienen problemas con el idioma.

Técnicas que pueden identificar esta preocupación:

* Deletrear con los dedos ha sido una capacidad muy útil para apoyar el aprendizaje del alfabeto de braille.

* Contar historias y textos basándose en las experiencias personales del niño o de sus intereses que puedan ayudar a entender el inglés representado por braille.

* Modificar el nivel del lenguaje al nivel de la habilidad del niño para leer y comprender el inglés.

13) *¿Hay estrategias, materiales, y herramientas instructivas comunes, que se usen con estudiantes sordos o que no puedan oír bien, que puedan presentar problemas para los estudiantes sordociegos?*

* Señalar con el dedo, expresiones faciales, gestos, demostraciones y modelos requieren cambios en la mirada.

* Si se usan tarjetas de señas y cuadros para enseñar las señas es importante determinar la mejor presentación: el color o la línea negra, contraste alto, aclaración de las figuras, la perspectiva, etc.

* Cuando se trabaja en el piso, el maestro frecuentemente pone las cuadros u objetos en el piso y luego hace las señas al nivel de su pecho. Exige que se vea en dos lugares y en dos diferentes distancias.

* El usar dos cuadros o dos objetos uno al lado del otro y moviéndolos para arriba y para abajo como una modificación de la seña "cuál". El niño que tiene pérdida de la vista enfrenta el problema de tratar de interpretar el movimiento de las cuadros.

* Filma/videos con encabezar=Captioned films/videos or computer aided real time (CART). Un niño con agudeza visual o restricciones de campo visual puede tener dificultad para leer Películas/videos, uso de la computadora y texto impreso.

* El TDD (dispositivo de telecomunicaciones para los sordos) puede necesitar adaptaciones en las teclas tales como una pantalla más grande. El dispositivo de Telebraille puede ser apropiado si el estudiante usa braille.

14) *¿Hay que identificar las modificaciones en la interpretación estándar o en la instrucción en el aula?*

Nota: esta es una discusión abreviada de los puntos importantes relacionados con los servicios de interpretación apropiados.

Es posible que una persona sordociega necesite una interpretación completamente diferente a otro estudiante sordo y que esté en la misma aula. Aun cuando todos estén haciendo señas, se puede necesitar apoyo adicional. Por ejemplo, en una conferencia recientemente cuatro participantes pidieron interpretación de señas. Uno de los participantes podía ver al intérprete en la plataforma que estaba al lado del orador. Dos de los participantes necesitaban intérprete de señas táctiles. El cuarto usó un intérprete de visión cercana. Se necesitaron tres formas diferentes de arreglos de interpretación simultánea, para poder hacer la información accesible a todos los participantes.

Adaptaciones sobre la interpretación:

* Interpretación en plataforma. El intérprete se ubica cerca del orador. Ellos pueden colocarse muy cerca o muy lejos del estudiante sordociego.

* Interpretación para grupos pequeños. El intérprete se sienta a unos 3 ó 4 pies del pequeño grupo de estudiantes. Esta adaptación de hace para los que la visión no les permite ver al intérprete en la plataforma.

* Interpretación de visión cercana. Este tipo de interpretación se da cuando la persona que tiene pérdida total de la vista requiere un lugar especial para la información. Este es frecuentemente el caso cuando una persona tiene restringidos

los campos visuales u otras limitaciones visuales que requieren que se hagan señas dentro de un espacio o distancia especial. Esto también ocurre cuando una persona necesita usar señas táctiles.

* Descripciones visuales. Cuando se interpreta para una persona que es sordociega (o se conversa con esa persona), el intérprete incluye descripciones de lo que él no puede ver ni oír.

* Interpretación táctil (ver pregunta # 11).

CONCLUSION

La elaboración de las adaptaciones y modificaciones apropiadas para un niño sordociego es importante para su logro educativo. Si estas necesidades únicas no se hacen, el niño, no importa dónde se encuentre, está en el ambiente más restrictivo. Se encuentra aislado de cualquier oportunidad para aprender. Desafortunadamente, estos apoyos no son siempre fáciles ni baratos.

Usted puede determinar qué apoyo se necesita para entender las formas manuales de comunicación, ayudando al equipo a desarrollar un tipo de programa que pueda beneficiar al niño con la educación y a tener acceso al programa, haciendo una evaluación completa del funcionamiento visual del niño.

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RECURSOS

National Family Association for Deaf-Blind Supporting Persons who are Deaf-blind and Their Families es una red nacional de familias que se dedican a los problemas de los sordociegos. Para información sobre cómo puede usted convertirse en miembro de NFADB, llame al 1-800-255-0411, ext. 275.

Hay un nuevo grupo de apoyo para padres de niños que tienen sondas para su alimentación. La meta de *Gut Instinct* es dar comprensión, apoyo, e información a las familias de niños con desórdenes gastrointestinales (GI). Para información, llame a Jan Williams al (210) 521-9743.

The Texas Department of Insurance ha publicado un folleto de 12 páginas que explica los derechos de los tejanos que tienen alguna incapacidad a que se les trate de manera igual y justa para la cobertura de seguro bajo la ley. Para conseguir una copia gratis de *What Texans with Disabilities Should Know About Insurance* = Lo que debe saber el tejano que tiene alguna incapacidad, llame al 1-800-599-7467.

Las familias que buscan servicios de relevo pueden encontrar estos servicios en **National Respite Locator Service** en cualquier área de U.S. El servicio tiene una base de datos de organizaciones a nivel nacional que prestan servicios de relevo en todo el país. Para más información, llame al 1-800-773-5433.

PARENT-TO-PARENT

Los padres de niños con limitaciones visuales del área de San Antonio pueden estar interesados en ser miembros de Alamo Area NAPVI. NAPVI es una organización que está dirigida totalmente por padres de niños que son invidentes o que tienen limitaciones visuales. Para más información, escriba a Alamo Area NAPVI, 8417 Bear Tree Circle, San Antonio, TX 78255.

Los padres del área de Lubbock tienen oportunidad de tomar parte en un grupo de apoyo para compartir información, inquietudes y compasión relacionado con tener a un niño con necesidades especiales. Póngase en contacto con Heaven's Very Special Children a través de Methodist Children's Hospital en Lubbock.

AVISOS CLASIFICADOS

DBMAT
Annual Fall Conference
and Family Retreat Weekend
= Conferencia Anual del Otoño y Fin de Semana
de Retiros para Familias
Octubre 13-15, 1995
Camp John Marc Meyer
Meridian, Texas

Habrá actividades organizadas para todos los miembros de la familia y habrá personas con experiencia para cuidar a los niños.

En la próxima edición de "*In Touch*", habrá una hoja de aviso e inscripción. Por favor llame al boletín de DBMAT Parent Connection al (214) 287-1904 (voz/fax).

Para mayor información sobre este fin de semana especial, por favor llame a DBMAT Parent Connection al (214) 287-1904 (voz/ fax).

Conferencia Estatal de PATH

Family Matters II:
Look Out for the Future

Octubre 6-7, 1995

San Antonio Airport
Hilton and Conference Center

Habrá 36 sesiones que identificarán las necesidades de los padres, los profesionales, y los educadores. Algunos de los temas sobre comportamiento son: ADHD, Sección 504, control de la tensión, comunicación con los legisladores, derechos y oportunidades... y mucho más

Para recibir un folleto con más información sobre esta valiosa conferencia, por favor llame a PATH al 1-800-866-4726.

Sexto Simposio Anual para Profesores
de las personas con limitaciones visuales:
***Helen called her "Teacher"* =**
Helen le Llamó "Profesora"

Octubre 6-7, 1995
Austin, Texas

Patrocinado por:

Texas School for the Blind and Visually Impaired

Temas:
* *Quality Programs for Students with Visual Impairments* = Programas de Calidad para Estudiantes con Limitaciones Visuales
* *Babies and Toddlers* = Bebés y Niños
* *VMI (Visually & Multiply Impaired)* = Personas con Limitaciones Visuales y con Incapacidades Múltiples
* *LMA (Learning Media Assessment)* = Evaluación de Medios para el Aprendizaje

Inscripción $35

Para más información, llame a Laura Baker, *TSBVI Outreach*, al (512) 206-9268

National Conference on Active Learning:
The Methodology and Philosophy
of Establishing Active Learning Environments for
Infant, Preschool and Multi-impaired Blind and
Visually Impaired Children
= Conferencia Nacional de Aprendizaje Activo:
La Metodología y la Filosofía del Establecimiento
de Ambientes de Aprendizaje Activo
para Bebés, Preescolares y Niños con Incapacidades
Múltiples y con Limitaciones Visuales,

tendrá lugardel 13 al 17 de noviembre,
en Seattle, Washington.

Para más información, llame a Sherry Raynor al (517) 333-1725.

CURSILLOS Y CONFERENCIAS

TCB y Region 20 Education Service Center patrocinarán en San Antonio ***HELP: Helping to Educate for a Lifetime of Possibilities*** **= Ayudando a Educar para Tener Posibilidades para Toda la Vida.** Llame a Kathleen Ford al (210) 299-2400 para más información.

SKI*HI Training tendrá lugar en la *Region XIII Education Service Center* del 18 al 21 de septiembre de 1995 (parte 1) y del 29 al 31 de enero de 1996 (parte 2). Para más información llame a David Ramírez al (210) 735-1214 o a Bárbara Talamantez al (210) 661-3354.

La Conferencia *The Discovery '95 NAPVI / Illinois Low Vision* tendrá lugar del 12 al 14 de octubre, en Chicago, Illinois. Para más información llame a *National NAPVI office* al 1-800-562-6265.

Getting in Touch with Literacy **= En Contacto con la Alfabetización: Conferencia Nacional sobre las Necesidades de las Personas con Limitaciones Visuales.** Tendrá lugar en Austin, del 7 al 10 de diciembre. Para más información, llame a Phil Hatlen al (512) 454-8631.

Otros Cursillos Patrocinados o Co-patrocinados por TSBVI

LOOKING AHEAD, transitions to adulthood experienced by students who are deaf-blind **= Mirando al Futuro, El Paso a la Edad Adulta Desde el Punto de Vista de los Estudiantes Sordociegos.** Tendrá lugar en Austin, el 23 de septiembre, en el *Austin Marriott at the Capitol*. En este boletín de *P.S. NEWS*!!! encontrará una hoja de inscripción. Llame a Beth Sánchez, al (512) 206-9103.

INSITE Training **= Entrenamiento en el Lugar.**
Se llevará a cabo en Corpus Christi, del 13 al 15 de noviembre (parte 1) y del 6 al 8 de diciembre (parte 2). Para más información llame a Joyce West, *Region 2 Education Service Center*, al (512) 883-9288, ext. 2246 o Gigi Brown, *TSBVI Outreach*, al (512) 206-9272

TECNICAS DE RELAJAMIENTO Y DE FORMACION DE VINCULOS (BART)

Tocar es una necesidad humana básica y los estudios de investigación indican la importancia de tocar, en el crecimiento saludable de los bebés y de los niños (Fields, 1992). BART está basado en el programa de educación para los padres de *Vimala McClure's Infant Massage* = Masajes para el bebé. Fue adaptado por Evelyn Guyer, RN, BSN, hace siete años, para identificar las necesidades de los bebés, de los niños y de otras personas mayores con necesidades especiales. Las técnicas se están usando en nueve estados, en Canadá, y en cuatro países europeos.

Una de las metas importantes del programa BART es reducir el nivel de estrés en el padre y el niño, o la niñera y el niño, también habilitar al padre y promover el respecto por el niño. Mediante un plano individualizado de caricias, BART identifica las muchas necesidades físicas emocionales y sensitivas de los niños que tienen demora en el desarrollo, o que están en riesgo de tenerla. Otros beneficios son el acercamiento, la mejor comunicación, el amor y seguridad que encuentran el padre y el niño, o la niñera y el niño. Aumentar la conciencia del cuerpo del mismo niño es especialmente importante si existen incapacidades físicas, como, limitaciones visuales y del oído o limitaciones de las habilidades motoras. Mejoran las funciones respiratorias, gastro-intestinales, sensoriales y también se ha visto que ha mejorado la organización del comportamiento.

El programa BART es un curso de capacitación para profesionales que trabajan con padres y familiares de niños con necesidades especiales. En un curso intensivo de dos días, los profesionales de las escuelas, agencias y los centros de intervención temprana aprenden las habilidades para convertirse en educadores de padres. Estos instructores de BART no practican con las manos. Solamente los padres hacen los masajes a sus niños.

BART es reconocido por la *International Association of Infant Massage (IAIM)* un programa especializado de gran valor. Después del curso, los instructores de BART son acreditados para dirigir sesiones individuales o en grupo con los padres y sus niños, enseñando a los padres y niñeras un plan específico para dar el masaje al niño.

El Entrenamiento BART tendrá lugar en Texas:

Octubre 23-24, 1995-El Paso
Octubre 25-26, 1995-Edinburg
Octubre 27-28, 1995-Houston

La matrícula vale $199

Para más información, llame a Evelyn Guyer al (716) 652-2763

IMPORTANTE: Si usted ya no lee este boletín o si recibe más de una copia, por favor, escriba o llame al 1-800-TSB-KARE. Dé el nombre y la dirección para cancelar las copias que no quiere recibir. Por favor, no tire los boletines que no quiere leer, páselos a otra persona.

The Texas School for the Blind and Visually Impaired no discrimina en el empleo ni en la prestación de servicios por motivo de raza, color , origen nacional, sexo, religión, edad ni incapacidad. P .S. NEWS!!! recibe algunos fondos de la concesión Federal, 34 CFR 307.1 1. El total de los fondos es $364,000 y se administran a través de *Texas Education Agency, Division of Special Education* .

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